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ABSTRACT

Two issues of this journal on education and related services for students with physical disabilities contain the following major articles or reviews: "Environmental Effects on Education" (Harold F. Perla); "Using Touch Math for Students with Physical Impairments To Teach and Enhance Beginning Math Skills" (Adrienne L. Duris); "Traumatic Brain Injury: A Five State Study of Special and General Education Preparation Experiences" (J. Keith Chapman); "Teaching Individuals with Physical, Health, or Multiple Disabilities, Fourth Edition: Review" (Mary Polancih); "Including Students with Severe and Multiple Disabilities in Typical Classrooms: Practical Strategies for Teachers (2nd Edition): Review" (Kathryn D. Peckham-Hardin); "The Physician's Guide To Caring for Children with Disabilities and Chronic Conditions: Review" (Fabian Gorodzinsky); "Someone Was Watching Over?" (Harold F. Perla); "Self-Regulatory Strategy Use of Children with Cancer in an Alternative Education Setting" (Andrea Crossland); "Service Delivery Practices and Educational Outcomes of the Related Service of Occupational Therapy" (Karin J. Barnes); "Educational and Psychosocial Implications Affecting Childhood Cancer Survivors: What Educators Need To Know" (Cathleen G. Spinelli); and "A Case Study of Three Professionals with Cerebral Palsy: Factors in Common" (S. John Obringer and Kenneth M. Coffey). (Individual articles contain references.) (DB)

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DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

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LETTER TO THE EDITOR

Dear Editor:

It was with great interest, and a sense of nervousness, that I read Steven Daley's President's Message, "Without a leg to stand on: The unraveling of a teaching specialty in special education" (*Physical Disabilities: Education and Related Services*, Volume XX, Number 2, Spring 2002). As I read from one page to the next, I wasn't quite sure if I was going to like what he said, and if I was going to feel comfortable with the stance he was taking as president of DPHD. However, I found myself not only nodding affirmatively, but also smiling by the end of the paper. I decided I'd better go back and read it again, just to be sure that I had a clear and accurate understanding of Dr. Daley's position, statements, and suggestions. This second time around left me even more satisfied that our president has taken a stand that can only help move the field forward and attempt to enhance the quality of education children of OI/OHI receive in schools.

I agree with Dr. Daley's emphases on: the need to reorganize special education at many levels beginning with personnel preparation programs in teacher education; the commitment to reconceptualize the delivery of services for students in many settings; and the message to CEC as a professional organization guiding us into this new century. As Dr. Daley pointed out, students with OI/OHI are in regular classrooms just as they should be. Therefore, the rest of the system must build the infrastructure that will allow for success—teachers who are prepared to understand OI and OHI and work with these students appropriately; services that follow the student in multiple classroom settings, and a professional organization that changes to create a strong membership base and supports the field in new ways through new structures.

I applaud Dr. Daley's strength and courage to extend himself and his beliefs beyond the role of merely providing leadership to a small, dwindling division within CEC. I am especially pleased that he has voiced the importance of educating children with OI/OHI in the regular classroom, and he has focused on developing a system of teacher training, partnerships, collaboration and consultation that will support the success of these students. The future of DPHD depends on the ability of the organization to attract and retain members—members who are committed to students with OI/OHI and

working on their behalf as productive participants in home, school, community, and vocational settings. Even if DPHD goes away or is recreated as a different organizational structure, those of us who share this commitment must insure that students with OI/OHI are taught in regular classrooms by teachers and related service personnel who are prepared to help them gain the knowledge and learn the skills they will need to succeed in life.

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GUEST PRESENTATION

ENVIRONMENTAL EFFECTS ON EDUCATION

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Court Appointed Special Advocate
Los Angeles, California

This is the second paper by the author to describe not only the trials and tribulations that might be encountered in cases where a child is under the jurisdiction of the Dependency Court, but what kinds of successes can often be obtained.

An introduction to the Dependency Court is presented here again for the benefit of those who may not have read the earlier paper (Good Things Happen, Volume XIX, Number 1, Fall 2000). The Dependency Court, a division of the Los Angeles County Superior Court, hears cases involving issues of child abuse and neglect. The court has responsibility for ensuring that all children under its jurisdiction receive appropriate care and services in the foster care system. The Department of Children and Family Services (DCFS) is the primary government agency charged with the responsibility of providing the children with needed care and services. With over 36,000 children currently in the court's jurisdiction, and every Children's Social Worker (CSW) carrying case loads of 50 to 60 children, each child receives limited attention. To help these children, and to assist the court in meeting its responsibilities to the children, the Superior Court founded the Child Advocates Office, a program comprised of a supervisory professional staff and volunteer Court Appointed Special Advocates (CASA).

CASA volunteers are appointed by judges to the cases of specific children. The role of the CASA is to gather comprehensive information about a child's needs and circumstances, report findings and make recommendations to the judge, monitor compliance of the court's orders, facilitate the provision of needed services, and advocate in court and in the community for the best interests of the individual child. A CASA usually carries one or two cases at a time, depending on a volunteer's time and availability. Since there

are currently about 300 CASA volunteers in the program, compared to over 36,000 children under the court's jurisdiction, only the most needy children have a CASA assigned to them.

At the start of this case, Steven was a 12-year old who lived with his mother in an apartment. He was initially removed from his home as a result of his witnessing a major confrontation between his knife-wielding father and his mother, coupled with accusations that Steven was abused by his father. Under the jurisdiction of the Los Angeles Dependency Court, Steven was placed in a foster home for two months before being returned to his mother's care, but still under the court's jurisdiction. His father has only communicated with Steven by telephone on occasion. Steven's half sister, 18-years old at the time, was living in the apartment and it had earlier been alleged that her stepfather, Steven's father, had molested her. At the time, she too was removed from the apartment and placed in a foster home before subsequently being returned to her home. After Steven was returned home, his sister had an argument with her mother who insisted that the sister obtain a job. The sister then moved out of the apartment and maintained little contact with her mother after that.

As a volunteer CASA, I was asked to look into the situation, to see if Steven was in any way at risk, whether he was receiving therapy as ordered by the court due to his witnessing the earlier confrontation between his parents, and to determine if he was receiving medication for his asthma and allergies.

My initial contact was calling Steven's CSW assigned to the case from the DCFS. She reported that things seemed to be in order, but that she had great difficulty in getting Steven's mother to return calls and in arranging to meet with her at their apartment. I too had difficulty in contacting Steven's mother, but eventually was able to arrange a home visit to tell Steven and his mother what my role would be, different from the CSW. During the visit, Steven's mother told me that the Medi-Cal that was authorized by the Dependency Court for Steven's medication had been canceled for some reason and she was having trouble getting it reinstated. She said that she had not yet started any therapy for Steven. She said that Steven was in the magnet program at his middle school that specialized in the performing arts, including music, which was of interest to Steven. His mother said, however, that the school was not doing a good job with Steven.

In conversation with Steven he mentioned that school was boring and sometimes difficult, but I was impressed with his interest in so many things. They included sports, musical instruments, science, computer, and many other areas. When asked what he wanted to do when he gets out of school,

he responded "be a musician." I asked him to play something for me on his piano or guitar, since he said that he had been taking lessons for both, and he did. I was not very impressed with what I heard, but said nothing about it. I did suggest that he seemed very smart and maybe he could become a professional, such as a doctor or lawyer and play musical instruments as a hobby. As he is 12 years old, I did not expect much response from Steven to the suggestion at the time.

My first task was to get Steven's Medi-Cal reinstated and I called the Department of Social Services, speaking to a supervisor and introducing myself on Steven's behalf. She informed me that there was a glitch in the computer system and he would be reinstated in a day. That was the case, and I told Seven's mother who immediately obtained Steven's medication.

With the Medi-Cal reinstated, I contacted Children's Hospital to inquire about getting Steven into some kind of therapy program there, covered by Medi-Cal. After a number of calls in which I explained Steven's prior traumatic experience, Steven was accepted into a University Affiliated Program there. The problem remaining was that Steven's mother had three jobs at the time and was not able to take him to the therapy. Since the court normally does not allow CASAs to take over responsibilities of the Department of Children and Family services, I had to petition the court to allow me to take Steven to weekly therapy in the early evenings. It was approved and I took him for many months until such time as Steven's mother was finally able to secure a firm daytime position, after which she took him to therapy sessions.

Having earlier noted that Steven's sister and mother had a falling out, there was a point in time after she left the home that Steven's sister had another argument with her mother and the sister called the DCFS hot line and falsely reported that her stepfather had molested her and abused Steven again. I had called the CSW late that afternoon on another subject, but she told me of the hot line call and that she was going to have Steven removed from school early the next day and place him in a foster home. Under the circumstances, the CSW rightfully took no chances that Steven might be at risk. Asking if she was going to call Steven's mother about the allegation and Steven's pick-up from school, she said she would. Unfortunately, because of Steven's mother's work schedule the CSW was unable to contact her and chose not to leave a message on her answering machine. Very distraught that night when she returned home and Steven was not there, Steven's mother called the police who immediately came to the apartment. That happened to coincide with the day a court hearing was held to review Steven's case. I had gone to the court that morning and was informed by Steven's court-appointed attorney that Steven had been removed from school that morning and the

hearing was canceled. It was not unusual that the CASA on a case has to find out things the hard way. Steven's mother called me late that night while the police were at her home, frantically telling me her son was missing. I informed her of what I had learned in court that morning and was shocked to hear that no one had called her about it. As it turned out, Steven's mother contacted DCFS and the court the next morning and convinced them that her daughter's call was a vindictive hoax and that none of the family had even seen Steven's father for some time. Steven was returned home that day and the CSW was reprimanded for her actions. She left the department shortly after that.

It was that experience in which she was not informed by DCFS that Steven had been picked up that caused Steven's mother to generally be uncooperative with the new CSW. She would only meet with the new CSW if I was present and had arranged for the meeting.

While all these actions were taking place, I had concern about Steven's schooling and met with his teachers and the head of the magnet program. I was told that Steven had a habit of "hamming it up" to get the attention of others and thereby disrupting classes. As far as the school providing for Steven's desire to continue with instrumental lessons, the school did not have such teachers and Steven had been assigned to a choral group. When the semester ended and I saw Steven's report card, he had failed sixth grade! That is when he, his mother and I discussed the possibility of Steven transferring to another magnet school, one possibly offering instrumental programs. That extensive pursuit by me was in vain because the magnet program priority point system that was based on a number of factors placed Steven on a long waiting list with little hope of success.

In the repeat year of school, Steven's report card still left a lot to be desired regarding his grades. I was still convinced of Steven's intellect and decided to pursue another route. I felt that getting Steven into a magnet program was not as important to his education as going to a school with a different environment. That is, a place where Steven could change his peer group that seemed to encourage him to act up to gain attention from others. I discussed this with his therapist and with his mother who both agreed that a change in school might be beneficial to Steven. I contacted all the schools that had noted music departments as suggested by administrators in the school district and that were not unreasonably far from Steven's home, assuming he could get bussed to the school. All of those schools had no open enrollments for the next year because they were filled to capacity and had to bus out many children in their neighborhood.

Finally, I sought the attention of the assistant principal at one of those schools, giving her the case background and convincing her of Steven's intelligence and the possible benefit to be obtained by transferring him. She finally consented to allow Steven's acceptance there and even arranged for his bussing, after which he began attending the school.

At the next court hearing a few months later, the DCFS recommended that Steven continue to be under the jurisdiction of the court because Steven's mother had not fully cooperated with the CSW. I argued that Steven's mother was doing everything that was in Steven's best interest, was a caring and dutiful mother, was steadily employed and her health insurance provided by her employer would take care of Steven's medical needs. I recommended that Steven be released from the court's jurisdiction and the judge agreed. That also concluded my formal involvement in the case.

At the end of Steven's first semester at the new school, his mother called me to say that she had just met with Steven's school advisor and teachers, and that Steven was now assigned to the school's honors program! Great news!

There are CASA programs throughout the country. If you are interested in participating in CASA activities in your area, please contact the National CASA Association at 1 (800) 628-3233.

Address correspondence to Harold Perla at perla27@earthlink.net or at the Superior Court, Child Advocates Office, 201 Centre Plaza Drive, Suite 3, Monterey Park, CA 91754-2158.

GUEST ARTICLE

USING TOUCH MATH FOR STUDENTS WITH PHYSICAL IMPAIRMENTS TO TEACH AND ENHANCE BEGINNING MATH SKILLS

ADRIENNE L DURIS
DeKalb County (Georgia) School System
2000–2001 ELIZABETH WETZEL AWARD WINNER

Being able to identify numbers, count, and solve basic addition and subtraction facts are skills needed in our daily lives. For students with physical impairments these skills can be a challenge for a variety of reasons. First, the student may lack the literacy skills to read and understand a math problem. Math is language based and requires students to not only read and understand a problem, but also respond to questions and explain the way a problem is solved (French, 1995). Students with physical and speech impairments, who use an Alternative and Augmentative Communication (AAC) device, need the necessary vocabulary on their device so that they can participate. Second, when students are learning numeral identification and how to count, they use manipulatives. This, too, can be an obstacle for students with a physical impairment. They may lack the fine motor skills to manipulate objects to count. For students with physical and speech impairment this also may affect students' ability to count. The teacher must make adaptations and teach instructional strategies, so that they learn how to count. Many students with physical impairments may tire easily or may have a health impairment, which may cause them to miss school or only be able to complete a limited number of problems. This may result in students missing important concepts and opportunities to practice the skills learned. The students may also have a concomitant visual, cognitive or perceptual impairment, which may require adaptations or specific instructional strategies to master beginning math skills. Despite these challenges, students with physical impairments can learn to identify numbers, count and solve basic addition and subtraction facts

with specialized curriculums, instructional strategies, modifications, software and assistive technology to meet their individual needs. One such curriculum/strategy is Touch Math. Touch Math is a multisensory approach to teach students addition, subtraction, multiplication and division (Bos & Vaughn, 1998; Bullock, 1989). The program uses dots on each number that the student must count. For example: one has one dot, two has two dots, three has three dots, four has four dots, and five has five dots. On numbers 6–9, there are some one dot, but there are some dots with a circle around it, which means you count that dot as two. Students are taught to touch each dot with their pencil (or for students with limited fine motor skills someone can point to the dots or, the students may use a body part to point to the dots) as they count. This paper will show that Touch Math is very successful for many students with physical impairments, as evidenced by: 1) it reinforces number identification and counting skills, 2) it is easy to adapt, 3) the dots can be faded over time, and 4) it helps teach addition and subtraction skills and fact mastery. Its use is cautioned for students who are unable to touch the dots because of physical limitations.

Touch Math can help reinforce and enhance numeral identification and counting skills. First, when introducing Touch Math, the student is taught to focus on the number and not the dots. One helpful strategy is: when the teacher is doing a lesson and showing demonstration and guided practice problems, the student can read the problem out loud first (or using their AAC device). This ascertains that the student is focusing on the number and is able to identify the number and not the dots. Touch Math also enhances counting skills by emphasizing rational counting. Since each dot 1–5 counts for one, this enables the student to practice counting numbers in succession. For a student who is nonverbal, who may have learned a jingle to rote count or count in succession, this too can be used when initially learning the dots. The concept of which number is bigger is also reinforced. In Touch Math, the student needs to identify which number is bigger and then count those dots and then count on from that number to the next number. An example would be: 1 + 2; the student would identify the numbers, then identify which one is bigger (in this case two) and count those dots first and then count up one to get their answer. A student who uses an AAC device could use it to identify which number is bigger, then count up and then indicate the answer using their device. Another counting and beginning addition and subtraction skill that is emphasized is adding one more and taking away one less. In Touch Math, students count on one more for addition and count backward one for subtraction. It can also reinforce the counting skills that are taught on a concrete level (by using real objects) by advancing it to a semi concrete

level (by using worksheets with problems with math dots and/or items to mark off, while counting) (Heller, 2001; Mercer & Mercer, 1998). This is because the student is counting not with real objects, but with dots and over time will touch the dots (or count them in their head for those who cannot touch the dots) when they are not there. This helps with learning and makes counting and numeral identification a skill that the student has mastered, and it can be carried over into other environments. For a student who may still have trouble with counting and numeral identification, Touch Math can still be used, but it is adapted so that the student has the opportunity to use real objects to understand what the numbers mean. For example: 4 + 1; the student would be shown four objects, so that he or she understands the number and then giving the student one more object is adding one more. After the student has mastered it with real objects, then he or she could practice it with the dots or the dots and objects to mark off on the paper. This helps reinforce counting and beginning addition skills on the concrete and semi concrete levels. One of my students who had difficulty with subtraction using Touch Math. I made the worksheets with the math dots and objects she could mark off as she subtracted. This helped her learn subtraction.

Touch Math is easy to adapt and is appropriate for many different students. With this curriculum, the teacher is given worksheets to use with the program. The teacher can adapt those worksheets to meet a student's particular needs. For a student who is unable to write numbers, but can mark with a pencil, the teacher can write the problems and have a series of three answer choices for the student to mark the correct answer. The teacher could use this as a distractor array and to help with error analysis to assure that the student understood the concept and answered correctly. For a student who has difficulty turning worksheet pages, flip rings could be added, so that the student could turn the pages of worksheets independently. Both of these adaptations help the student with developing independent work habits. One other advantage with Touch Math is that the dots are large enough, so that the students can see them and they are useful for students with visual impairments or perceptual problems. One strategy that is helpful when a student is first learning Touch Math is to use black to write the number and orange to write the dot. This helps the student be able to differentiate between the dot and the number and is helpful for students with visual and perceptual problems. However, its use is cautioned so that the student is not focusing on the dots, but rather on the number. Moreover, it could also be confusing to some students. Another way to adapt Touch Math is that a student who uses an AAC device could solve the problems and when they got to the end of the worksheet page, they could indicate that they were done and then someone could

write the answers and turn the page for them. One of my students would be given 3–4 problems to complete independently. When he was done, he would say, "I am finished" with his AAC device. This helped him develop independent work habits.

One important aspect of Touch Math is that the student does not become reliant on the dots. This is why it is important to fade the dots as soon as possible. This is one plus with the program. After the student learns to touch the dots with a pencil, someone pointing, finger/body movements, count in his or her head, etc, the dots can be faded and then the student will still count the dots without the dots being there. With my student who was unable to touch the dots, initially the paraprofessional or I touched the dots for him while he counted in his head (aloud with speech approximation or counted the dots with his fingers). This was very successful, especially with dots 1–5. But over time he learned to count the dots 6–9. But what was particularly helpful was that he would count the big number first and then count up that many more dots. This helped him greatly not only with his counting skills, but also with his addition skills. I have found it useful to initially make the worksheets using a big marker, but then over time, I used a smaller bold tip pen and made the dot smaller and the dot with a circle around it a dotted line. One of my students with visual and perceptual problems used it this way, which was helpful and it enabled me to start fading the dots for her. It is crucial in this stage that the student continues to focus on the number, but to continue doing the touch points with a pencil, in his or her head or with a body movement.

Touch Math can also be used to teach addition and subtraction skills to reinforce fact mastery. Although the Touch Math curriculum provides worksheets, I have found it useful to create my own worksheets. I also teach my students beginning addition using the following sequence: Zeroes rule, 1's rule, doubles, adding sums to 10 and then adding numbers to 18. For subtraction, I teach the Zeroes rule, doubles, 1's, subtracting differences from 10, and then subtracting differences from 18. This not only helps the students get accustomed to the numbers, but it helps with fact mastery. Also, I can teach different math concepts with each stage. For example when teaching the ones rule in addition, I can teach the concept of counting up. I have seen progress with following the above addition and subtraction sequences, especially when fading the dots and with fact mastery.

One disadvantage with Touch Math is that it may not be appropriate for all students with physical impairments. This is especially the case for students who are unable to touch the dots. I have found it useful to have someone point to the dots for the student, or if he or she is able, can count the dots

with fingers or a body movement and then the student can learn to count the dots in his or her head. I have found that the dots 1–5 are easier to teach and fade than dots 6–9. I have also found it helpful, in addition to using Touch Math, to provide students opportunities to practice their counting and beginning addition and subtraction skills by using software counting programs (i.e. Mighty Math: Carnival Countdown; Mighty Math: Zoo Zillions; Millies Math House all by Edmark, and Number Concepts 1 by Intellitools). These programs reinforce counting, basic addition and subtraction skills. They are especially helpful for students who may be unable to touch the dots and may use an alternative input device (i.e. a switch) to access the computer, because they enable the student to move items across a computer screen. This is helpful when teaching counting and beginning addition and subtraction skills. It also helps develop skills that are necessary for higher-level math skills. If a student were unable to use Touch Math (or it proved to not be beneficial because of physical access issues), I would try Intellimathics by Intellitools along with Math Pad by Info Use. This is because Intellimathics uses on-screen manipulatives, which is helpful for students who are unable to physically use manipulatives, learn to count and do basic addition and subtraction problems. However, I would first try Touch Math, because these other software programs and assistive technology devices are not always available and I have found some success with Touch Math with students who are unable to physically touch the dots, but can count with someone pointing, using their fingers or count in their head.

Students with physical impairments need to learn to identify numbers count and solve basic addition and subtraction facts. One way to teach these skills is through the use of Touch Math. Touch Math can not only reinforce these skills, but also incorporate independence skills. It should be cautioned; however, that some students with limited fine motor skills may require additional modifications or a different program after trying Touch Math and realizing that it may not be the best program for that student.

THE MATERIALS LISTED IN THIS ARTICLE CAN BE OBTAINED:

Millie's Math House, Mighty Math: Carnival Countdown, Mighty Math: Zoo Zillions all by Edmark available from Edmark (http://www.riverdeep.net /edmark/)

Intellimathics and Number Concepts I by Intellitools (http://www. intellitools.com)

Math Pad by Info Use (http://www.intellitools.com)

Touch Math by Innovative Learning Concepts (http://www.touchmath.com)

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TRAUMATIC BRAIN INJURY: A FIVE STATE STUDY OF SPECIAL AND GENERAL EDUCATION PREPARATION EXPERIENCES

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ABSTRACT

A sample of special and general education professionals who worked in Alabama, Florida, Georgia, Louisiana and Mississippi were surveyed to determine service patterns and preservice/inservice preparation experiences regarding working with and addressing the needs of students who had experienced a traumatic brain injury (TBI). Of the 300 surveys distributed, 192 responded, for a return rate of 64%. Across the two professional groups, overall findings suggested a lack of meaningful educational preparation in working with this population of students. In addition, needed additional educational experiences and competency areas were identified.

In the mid-1970s when PL 94-142, Education of the Handicapped Act (ERA) was originally passed, it did not specifically mention the needs of individuals with traumatic brain injury (TBI). When the law was amended in 1990 as PL 101-476, the Individuals with Disabilities Education Act (IDEA), TBI was added as a new disability category. The law also authorizes a broad variety of special education and related services to include, among others, specially designed instruction, assistive technology, physical and occupational therapy, speech pathology, and special education. These services are free and must be provided within a 30-day window once the need(s) has been identified. Within this context, IDEA defines TBI as:

> *an acquired injury to the brain caused by an external force, resulting in total or partial functional disability or psychological impairment, or both, that adversely affects a student's educational performance. The term applies to open and closed head injuries resulting in impairments in one or more areas, such as cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem solving, sensory, perceptual, and motor abilities, psychosocial behavior, physical functions, information processing, and speech The term does not apply to brain injuries that are congenital or degenerative or brain injuries induced by birth trauma* (Federal Register, vol. 57, no. 189, p. 44, 802).

While most TBIs are mild (Koch, Metz, & Lynch, 1995), the incidence statistics are significant from a social and educational perspective. For example, the *Brain Injury Association* (1999) estimates that each year approximately 5 million individuals in this country experience a head injury. Of this number, approximately 3–5% (200,000–250,000) will require hospitalization due to severe complications as a result of the head trauma. One in every 30 school age children will experience some form of a significant head injury before they are 16 years of age, and 40% of all head injuries that occur involve children (Forkosch, Kaye, & LaPlante, 1996; Hill, 1999). Each Year, there are enough reported cases of children who experience a severe TBI, that it has become the most common acquired disability in childhood (Bigge, Best, & Heller, 2001).

The etiology is clearly exogenous in nature as factors causing a TBI across all age groups are attributed to such causes as automobile-related accidents, falls, sporting injuries, and neglect/physical abuse (Chapman, 2001; Novack, 1999; Savage & Wolcott, 1994). Young males under the age of eighteen have the highest incidence rates of experiencing the head injury (Turnbull, Turnbull, Shank, & Leal, 2001). The rate of mortality for TBI is 30 per 100,000, with 50% dying within the first two hours following the accident or insult to the brain (Hardman, Drew, & Egan, 2002). For those who survive, the greater the severity of insult, the more likely there will be long-term changes in physical, cognitive, and/or behavioral functioning (Hill, 1999).

There are significant problems attaining precise data regarding the number of students who are developmentally affected by a TBI and where they are receiving services (Chapman, 2001 ; Savage & Wolcott, 1994). The *Twenty-Second Annual Report to Congress* indicated that approximately 12,000 children and youth with TBI (6–21 years of age) were served in special education programs during the 1998–1999 school year (U.S. Department of Education, 2000). Although these yearly reports have consistently com-

municated a small increase in the number of students served, when one considers TBI incidence statistics, these reported data are surprisingly low.

What differentiates a TBI from other disabilities is its variance in developmental effects. Each individual case is unique, and the effects are dependent on a number of factors such as the intensity of the brain's movement within the skull and/or the area of the brain insult during the trauma event. Concentration problems, memory loss, difficulty with information processing, speech and language, seizures, self-regulation issues, personality changes, vision problems; any of these and more may be present. To further illustrate, the prefrontal cortex (frontal lobe) specializes in monitoring abilities such as impulse control and planning. Persons who experience a severe TBI, with damage to this area of the brain, may exhibit an inability to control behavior (e.g., gratification) and/or planning a course of action (Bowe, 2000). In addition, there can be a number of secondary complications (e.g., seizures) associated with a TBI (Farmer & Peterson, 1995).

Among other ramifications of a TBI are the progressive/plateauing and individual specific nature of the injury. The student may have the same overall cognitive abilities as before yet exhibit a loss of capacity to remaster certain abilities or concepts. Bowe (2000) suggests that while a TBI presents individual differences, as a group, recovery of functioning is rapid during the first year. Over time, there can be a plateauing effect, with little or no progress for long periods of time. In fact, while some students will exhibit major developmental gains, others remain deficient in diverse developmental areas which will affect their academic performance. From a psychosocial perspective, some students may experience significant behavioral problems (Iverson & Osman, 1999) such as episodes of emotional lability related to their awareness of past abilities and now exhibit frustration due to their current limitations (Kehle, Clark & Jenson, 1996).

A major challenge facing our educational system is providing functional learning experiences and coping strategies for students who have experienced a TBI in diverse settings. According to Chapman (2000) and Clark (1996), when a child or youth with a TBI enters or re-enters the school setting, the educational focus should be centered on providing for individualized intellectual, behavioral and environmental needs. However, due to the numerous problems often exhibited by these students (i.e., seizures, need for physical therapy), in association with the educational system's lack of a conceptual and/or practical understanding as to why and how these to students may have changed cognitively, behaviorally, and/or physically, the school reintegration process is complicated.

Savage (1997) identified two major barriers to successful educational integration or reintegration of students with a TBI: (1) lack of school readiness to serve this population, and (2) the lack of teacher preservice conceptual and/or structured supervised hands-on practical experiences. A number of studies (Abbot & Wilkinson, 1992; Chapman, 2000; Fanner & Peterson, 1995) suggest many teachers may lack a firm knowledge and experiential base regarding: (a) intervention techniques, (b) classroom flexibility and environmental needs, and (c) supervision and collaborative skills in functionally working with students who have experienced a TBI.

PURPOSE OF THE STUDY

There has been relatively little research attempting to describe the types and extent of preservice/inservice development educational-based personnel have received in working with students with TBI, particularly in school settings. Within this context, the purpose of this study was to obtain state-of-the-art descriptive information from general and special education professionals who are currently providing educational opportunities and experiences to school-aged youth (ages 6 to 21) in school-based programs in the states of Alabama, Florida, Georgia, Louisiana, and Mississippi to ascertain:

1. The types and the effectiveness of educational preparation and experiences these two groups have received regarding students with TBI.
2. To identify concerns and needed additional educational competencies these two groups consider to be important in effectively meeting the needs of this population.

METHOD

SUBJECTS

Participation in the study involved two educational-based groups (N = 300) located in four southeastern states. General education teachers (GEN) (n = 150) and special education teachers (SPE) (n = 150) were randomly selected from the 1999 *Alabama, Florida, Georgia, Louisiana and Mississippi Education Association Directories*. Inspection of the computer initiated sample and their mailing location indicated that each sample met the inclusion cri-

teria, and there were no duplication of addresses for either GEN or SPE group.

Instrument

The 12 item instrument (see Appendix) used for data collection purposes was designed by the researcher. The initial draft of the questionnaire was reviewed by several professionals who are knowledgeable about TBI. The survey was redrafted using their feedback. To verify instrument and survey procedures, the questionnaire was also pilot tested employing 40 individuals (four each in the two groups across the 5-state region) who were similarly situated to the subjects of the study, and who were providing school-based educational services to school-aged youth. A follow-up procedure was conducted after a 4-week interval. Of the 40 pilot questionnaires mailed, 27 were returned, for a response rate of 68%. Feedback from pilot test respondents resulted in two minor revisions in the organization of the questionnaire. No revisions regarding any individual items were suggested.

Part I of the instrument consisted of demographic data where respondents provided data regarding gender, ethnicity, educational level, degree emphasis, current educational position, and number years of teaching experience. The last section of Part I consisted of two forced-choice questions asking respondents: (1) if they were presently teaching individuals with a TBI, and (2) if they had experience in working with individuals with a TBI.

Part II asked respondents to indicate the types of preservice/inservice experiences they have received in working with individuals with TBI. Respondents were also asked to rate on a 4-point Likert-type scale (1 = Not Effective, 2 = Not Very Effective, 3 = Somewhat Effective, 4 = Effective), the effectiveness of these preparation experiences. The last section of Part II consisted of one forced-choice question asking respondents if they felt professionally prepared in working with students with a TBI.

Part III consisted of two open-ended questions. Question 1 asked respondents to describe their greatest concerns regarding providing services this population, and question 2 asked respondents to identify additional preparation areas they perceived as important in their professional development in working with individuals with TBI.

Procedure

Questionnaires were mailed to randomly selected general and special education professionals in educational programs. Follow-up letters, questionnaires, and stamped return materials were sent to those not responding after four

weeks and again after eight weeks. Of the 300 questionnaires that were mailed, 192 were returned, for a response rate of 64%.

Data Analysis

Descriptive statistic procedures and content analysis were conducted on the data obtained in this study. Descriptive statistics, from hand-coded raw data, were obtained by running simple computer statistical components (SAS Institute, 1998). Content analysis was applied to organize data from the open-ended questions by bracketing, categorizing, and sorting the data according to the primary theme or idea exhibited (Johnson & LaMontagne, 1993).

RESULTS

Subject Demographics

Seventy special educators (SPE) (female = 89%; male = 11%) and 122 general educators (GEN) (female = 90%; male = 10%) participated in this study. A significant majority of SPE (83%) and GEN (89%) were Caucasian with 17% of SPE and 11% of GEN identified as African-American. Interestingly, no other ethnic composite was identified. Twenty-five of the SPE group (36%) were identified as resource-room teachers within the elementary school, 3 SPE educators (4%) indicated that they were co-teaching in inclusive elementary settings, and 42 SPE professionals (60%) were identified as teachers in self-contained SPE classrooms. Similarly, eighty-five professional (67%) indicated they were elementary classroom teachers, 20 were identified as secondary teachers (16%), and 17 (14%) identified themselves as school administrative/support staff.

Regarding average years of teaching experience, the SPE group presented average of 3.5 years and GEN professional indicated 12.5 years of experience. Fifteen SPE teachers (21 %) and 18 GEN teachers (15%) indicated that they were currently providing classroom services to individuals with a TBI. In addition, 10 SPE teachers (14%) and 8 GEN teacher (7%) indicated that they had worked with this population in the past.

Types and Effectiveness of Educational Experiences

As Table 1 indicates, conferences/seminars and journals/printed materials were the most frequent types of educational experiences reported by SPE and GEN professionals. A majority of both categories rated these developmental

experiences as *somewhat effective*. Both professional groups rated other experiences as *not effective-to-not very effective*. Additionally, a small number of the SPE group (11.4%) did report opportunities for inservice/workshops regarding TBI. Overall, these experiences received *not effective* ratings. The GEN group did not report any program inservice or workshop opportunities. More accurate data may have resulted if precise certification categories of educational based respondents had been provided.

The last section of Part II consisted of one forced-choice question regarding perceptions of their educational preparation to work with students with a TBI. A small percentage of both professional groups (SPE 12%, GEN 7%) stated that they felt their educational development had prepared them to provide services to this population.

Concerns and Additional Educational Preparation Areas

Part III consisted of two open-ended questions. Question 1 asked respondents to describe their greatest concerns regarding providing services to this population. The five most prevalent identified concerns within a educational category, the rank order, frequency and percentages were tabulated. As Table 2 indicates, SPE identifying concerns focused toward areas related to the lack of diverse educational needs (87.1%), the lack of educational opportunities (77.1%), technology (74.2%), assessment (58.5%) and supervised practicum (57.1%) issues. GEN professionals also related concerns regarding practicum experiences (77.8%) and course work (52.4%). However, GEN professional seemed more inclined to acknowledge a more inclusive approach as these educators ranked legality (69.6%), collaboration (60.6%) and community resources (58.1%) within their top concerns in working with students with a TBI.

Question 2 asked respondents to identify additional preparation areas they perceived as important in their professional development in working with this population. As Table 3 indicates, both groups reported similar perceptions regarding additional preparation need areas with course work (SPE 91%, GEN 80%), practicum experiences (SPE 83%, GEN 76%), and collaboration (SPE 71%, GEN 61%), being consistently identified. When other preparation areas are considered between groups, SPE tended to identify methodological issues (intervention models, assessment, technology). Again, GEN professionals tended to identify inclusive areas such as legal issues and community resources.

TABLE 1.
Types and effectiveness of educational experiences

Professional Category	Type of Educational Experience	Number, Percent, Means of Professionals Response: Group Responding			Percentage of Professional Discipline Responding: Effectiveness of Educational Experiences				
					NR	NE	NVE	SWE	EFF
	(N = 192)	n	%	M	0	1	2	3	4
SPE	Conference/Seminars	60	85.7	2.63	14.2	4.3	28.6	47.2	5.7
(n = 70)	Inservice Activities	8	11.4	1.25	88.6	8.5	2.9	—	—
	Workshops	8	11.4	1.50	88.6	5.7	5.7	—	—
	Journals/Printed Materials	55	78.6	2.67	21.4	—	28.6	47.2	2.9
	Personal Experience	5	7.1	1.40	92.8	4.3	2.9	—	—
	Course Work	12	17.1	1.50	82.8	8.6	8.6	—	—
GEN	Conference/Seminars	80	65.5	2.46	34.4	—	35.2	30.4	—
(n = 122)	Inservice Activities	—	—	—	100.0	—	—	—	—
	Workshops	—	—	—	100.0	—	—	—	—
	Journals/Printed Materials	105	86.1	2.43	13.8	13.1	22.1	51.0	—
	Personal Experience	3	2.5	1.33	96.8	1.6	1.6	—	—
	Course Work	5	4.1	1.80	95.9	1.6	2.5	—	—

TABLE 2.
The five highest ranked identified concerns

What are the most significant concerns you have regarding providing services to students with a TBI?

Identified concern SPE (n = 70)	n	%	*Identified concern GEN (n = 122)*	n	%
A lack of knowledge of the diverse educational needs in TBI	61	87.1	A lack of hands-on/supervised experiences with TBI	95	77.8
A lack of course work/conceptual understanding of TBI	54	77.1	A lack of knowledge of legal responsibilities in the classroom	85	69.6
A lack of knowledge regarding technology with this population.	52	74.2	A lack of knowledge of teaming/ collaboration in TBI.	74	60.6
A lack of knowledge regarding assessment with this population.	41	58.5	A lack of knowledge regarding community resources for this population.	71	58.1
A lack of hands-on/supervised experiences with TBI	40	57.1	A lack of course work/conceptual understanding of TBI.	64	52.4

TABLE 3.
Group Perceptions of Additional Educational Need Areas

If any, what additional preparation areas do you perceive as important in working with students with a TBI?

Educational Group Special Education (n = 70)			*Educational Group* General Education (n =122)		
Need Area Item Statement			Need Area Item Statement		
Rank Order	*n*	%	*Rank Order*	*n*	%
Course work related to characteristics & educational needs in TBI.	64	91%	Course work related to legal issues/ responsibilities in TBI.	98	80%
Practicum/hands-on experiences.	58	83%	Practicum/hands-on experiences.	93	76%
Course work and practical experiences in teaming/collaboration in TBI.	50	71%	Knowledge related to community resources in TBI.	87	71%
Knowledge & practical experiences in technology.	47	67%	Course work and practical experiences in teaming/collaboration in TBI.	74	61%
Knowledge of intervention models/ assessment in TBI.	45	64%	Course work related to characteristics & educational needs in TBI.	68	56%

DISCUSSION

The purpose of this study was to provide state-of-the-art descriptive information concerning preparation patterns and needs of two groups of school-based professionals regarding providing services to students with TBI. Demographically, the greatest disparities centered on the gender differentials, ethnic representation, and teaching experience differential between SPE and GEN professionals. In fact, this survey found that a gender disparity was exhibited by both educational groups as 172 (90%) were female and 20 (10%) were male. Further disparities were indicated regarding ethnic representation of teachers as 166 (86%) were Caucasian and 26 (14%) were from minority groups. In addition, the average years of teaching experience for GEN professionals was 12.5 years as opposed to 3.5 years for SPE teachers, which is approximately a 4-to-1 differential. When one considers the changing dynamics in the ethnic composition of students, and the move towards a more inclusive classroom philosophy regarding students with diverse disabilities, these are important factors to consider in the recruitment and training of personnel in special and general education preparation programs.

This investigation was guided by the study's two objectives. The first objective was to describe the types and the effectiveness of educational experiences these two groups have received regarding students with TBIs. As Table 1 indicates, none of the GEN group and only a small percentage of SPE educators had experienced program inservice or workshop opportunities. Those SPE educators who had participated in these opportunities rated them *not effective*. Similarly, it was reported that only 12 SPE (17.2%), and 5 GEN educators (4.1%) had received any coursework regarding individuals with a TBI. Furthermore, a small number of both groups indicated that they were adequately prepared to work with students with a TBI.

One possible explanation may be noted in research studies conducted by Chapman (2000) and D'Amato and Rothlisberg (1996). These authors found that only recently have school districts actually addressed TBI from within the context of appropriate services and inservice preparation. While a wide range of options are often required to best serve the diversity of students with TBI, D'Amato and Rothlisberg (1996) actually found that many school districts had taken the position that all individuals with a TBI can be served in the regular classroom settings with existing personnel. At the building level, Chapman (2000) found that there has been little collaboration across agencies (hospital-to-school) or professional school-based inservice development regarding TBI. As a consequence, many educators do not

understand the conceptual, methodological, and diverse behavioral and physical needs of this population.

The two predominant reported educational opportunities for SPE and GEN centered primarily on conferences/seminars and journals/printed material (e.g., governmental reports). The foundation for this response may come from demographic data regarding years of teaching experience. As previously stated, GEN educators exhibited approximately a 4-to-1 ratio in the number of years in the field of education. As such, TBI may not have been a component of GEN preservice conceptual and/or practical educational experiences. In contrast, SPE respondents averaged 3.5 years of experience, and one would think that TBI would be part of their preservice preparation.

The second objective of this study was to identify concerns and needed additional educational areas. As identified in open-ended questions 1 and 2, both groups reported concerns and identified additional preparation areas related to their perceived lack of experience and opportunities to facilitate their professional development. Both groups also reported concerns and preparation areas related to intervention strategies. These concerns and identified preparation areas are not surprising when one considers that a majority of both groups indicated that they are not adequately prepared to work with students who have experienced a TBI. However, preparation areas reported by both groups seem to be no more than a partial representation of the competency foundation (e.g., collaboration) that these educators should have received as preservice/inservice preparation experiences.

These findings are reflective of research conducted by Chapman (2000) and Radar, Thomas, and Lenk (1995) in which it was noted that many special education teacher preparation programs do not have systematic instruction and experiences in TBI as part of a degree curriculum. These findings are further supported by a parallel study conducted by Savage and Wolcott (1994) which found that only a small percentages of special educators and general educators surveyed in urban settings had received any course work or supervised hands-on experiences with students who had experienced a TBI. As such, this may further explain the reliance of both professional groups on conferences and journals/printed materials.

CONCLUSIONS

Results from this study are exploratory and the limitations inherent to survey methodology must be considered when interpreting these results. One weakness of this study centers on reporting data regarding the types and effectiveness of educational experiences. Analysis would have been more accurate if

precise certification categories had been provided. Another weakness is that the questionnaire did not ask the extent of preservice training (e.g., entire course or one lecture). There is a possibility that the low effective rate in the course work category (Table 1) may be attributed to the amount of time TBI was covered in course work rather then it being an ineffective delivery mode.

Even so, the results from this study do extend our knowledge of possible determinants on professional development, and as such, have implications for teacher preparation and inservice programs. It appears that many SPE and GEN professionals within school-based programs in this 5-state region: (a) may lack adequate preparation in providing educational-based services to students with TBI, (b) have and are providing services to these students, (c) perceive that they are not adequately prepared and need further preparation to work with this population, and (d) reported a number of additional preparation areas that should already be intact components of teacher preparation programs. These findings should challenge teacher preparation programs and school districts to include diverse activities, materials, and information designed to enhance the education professional in conceptualizing their roles and responsibilities with this complex population of students.

The focus of this study was limited to school-based programs in a 5-state region. Additional information needs to be collected from a broader array of educators and related service providers (e.g., school administration) within diverse demographic compositions at regional and national levels. Moreover, research studies in this area need to be expanded and replicated in order to ascertain a broader conceptual foundation and practical framework regarding preservice/inservice development for those who must provide services, and provide a valuable empirical base on which to enhance the development of a comprehensive system of educational and related services for those who experience a TBI.

APPENDIX

Traumatic Brain Injury Survey: Elementary Education (GEN) and Special Education (SPE) Professionals

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Please respond to the following questions

I. DEMOGRAPHIC INFORMATION

1. *Gender:*

	ELEM	SPE
Male	_____	_____
Female	_____	_____

2. *Ethnicity:*

	ELEM	SPE
African-American	_____	_____
Caucasian	_____	_____
Hispanic-American	_____	_____
Native-American	_____	_____
Oriental-American	_____	_____
Other: _____	_____	_____

3. Please indicate your highest degree attainment.

Type of Degree:	ELEM	SPE
High School	_____	_____
B.A./B.S.	_____	_____
M.A./M.S.	_____	_____
ED.S.	_____	_____
Ed.D./Ph.D.	_____	_____

4. Please indicate your primary area of certification:

Type of Certification:	ELEM	SPE
Preschool	_____	_____
Kindergarten	_____	_____
Elementary	_____	_____
Secondary	_____	_____

5. What is your current educational position?
(i.e., elementary teacher)

ELEM _____

SPE _____

6. How many years of teaching experience?
(i.e., 2 years–4 months)

ELEM _____

SPE _____

7. Are you currently providing educational services to students with a traumatic brain injury (TBI)?

ELEM Yes ___ No ___
SPE Yes ___ No ___

8. Do you have experience in working with students with a TBI?

ELEM Yes ___ No ___
SPE Yes ___ No ___

II. TYPE OF PREPARATION AND ADDITIONAL NEED AREAS

A. Please check the types of preparation you have received in regard to working with students with a TBI, and indicate how effective these experiences were.

Preparation Area	*Not Effective*	*Not Very Effective*	*Somewhat Effective*	*Effective*
—Conference/Seminars	1	2	3	4
—Coursework	1	2	3	4
—Inservice Activities	1	2	3	4
—Workshops	1	2	3	4
—Journals/Printed Materials	1	2	3	4
—Personal/Professional Experience	1	2	3	4

B. Do you feel that you are professionally prepared to work with students who have experienced a TBI?

ELEM Yes___ No___
SPE Yes___ No___

III. CONCERNS AND ADDITIONAL PREPARATION AREAS

1. What are your greatest concerns in working with students who have experienced a TBI?

2. What are additional preparation area(s) you perceived as important in the professional development of educators in working with individuals with a TBI?

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TEACHING INDIVIDUALS WITH PHYSICAL, HEALTH, OR MULTIPLE DISABILITIES, FOURTH EDITION

June L. Bigge, Sherwood J. Best, and Kathryn Wolff Heller
Merrill Prentice-Hall, Inc. 2001
620 pages, $60.00

REVIEW

The texts written by June Bigge have long been important working references in my professional library. As a teacher of students with orthopedic impairments working in a state with no training programs in the area of physical, health or multiple disabilities, I have frequently been asked to help a newly hired colleague learn the job. June's most recent edition has always been the first book loaned to that new teacher. June Bigge's new partnership with Sherwood Best and Kathryn Wolff Heller brings together three of the most knowledgeable teacher educators in our field. Together they have brought the text into the twenty-first century, without losing the utility of earlier editions.

In the preface Bigge, Best and Heller begin with the reminder that "individuals with physical, health or multiple disabilities participate in all educational and community venues." The authors have taken on the daunting task of creating a text that can be useful to the many and diverse professionals who provide services to individuals with physical, health or multiple disabilities. But they have primarily directly addressed teachers, at both the inservice and preservice levels. Bigge, Best and Heller, along with a strong group of contributing authors, have succeeded in creating a comprehensive volume of information needed to teach individuals with physical, health or multiple disabilities in a variety of settings.

All three primary authors have long been active members of Council for Exceptional Children and the Division for Physical and Health Disabilities. It is not surprising that they have thoroughly incorporated the 1998 CEC document *What Every Special Educator Must Know: The International Standards for the Preparation and Certification of Special Education* and the "Specialized Knowledge and Skills in Physical and Health Disabilities" into the structure and content of the text. The use of these documents contributes

to the logical organization of the book, and brings many of the knowledge and skill statements to life for the reader who may not yet be familiar with them.

In this new edition, the authors have maintained the clear, concise style of previous editions. They have continued the strong emphasis on providing the practical, "real life" strategies that I have so greatly appreciated in past editions. Extensive use of illustrations, tables, charts, diagrams, sample forms and assessment tools, as well as a variety of internet resources support diverse learning styles and varied professional needs. In past editions, two areas of particular strength have been the thorough considerations of assistive technology and augmentative communication. A chapter on assessment of the need for assistive technology has been added to this edition.

Contributing author Penny Reed, with Sherwood Best, thoroughly address this complex subject. As a bonus, Reed and Best provide a complete assessment document that will help prepare the reader to participate in such a comprehensive evaluation when the need arises.

As one would expect, curriculum and instruction are extensively addressed. In this edition, eight chapters are devoted to different curricular areas. The reader is provided a solid base of related learning theory, current instructional approaches and best practices for each area. Then a variety of modifications and alternative instructional strategies are provided to address the diverse needs of individuals with physical, health or multiple disabilities. It is in these chapters that the depth and breadth of experience provided by June Bigge, Sherwood Best and Kathryn Wolff Heller shines through. It is very clear that these folks know what, and who, they are talking about. Even experienced teachers in the field will find useful information in these chapters.

It is my hope that beyond the audience to whom the authors have addressed this text, there will be others, especially school district administrators and educational policy makers, who will be exposed to this book. *Teaching Individuals with Physical, Health or Multiple Disabilities, Fourth Edition* provides a comprehensive explanation of the unique role of teachers working with individuals with physical, health or multiple disabilities, and the knowledge and skills they must have to do the job well. If this text cannot demonstrate the need for trained and experienced professionals in the field, then how can it possibly be done? June Bigge, Sherwood Best and Kathryn Wolff Heller have done our small corner of special education a great service by creating this text. Now it is up to each of us to make sure it gets to the professionals who need to read it.

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INCLUDING STUDENTS WITH SEVERE AND MULTIPLE DISABILITIES IN TYPICAL CLASSROOMS: PRACTICAL STRATEGIES FOR TEACHERS (2ND EDITION)

June E. Downing with Invited Contributors,
2001, Paul H. Brookes Publishing Company
ISBN 1-55766-519-2
$39.95, 267 pages

REVIEW

Including Students with Severe and Multiple Disabilities Typical Classrooms: Practical Strategies for Teachers (2nd Edition), is an excellent resource for teachers and support staff who are interested in facilitating inclusive educational opportunities for students with severe and multiple disabilities. As the authors state, the purpose of this book is to provide educators, family members and support staff "with strategies they can use successfully to include students with severe and multiple impairments in the typical learning environment of public schools on a full time basis (p. 12)." Clearly, the authors succeeded in their efforts. This book is replete with specific and concrete examples of curricular adaptations and ways to use assistive technology to ensure that the student's participation in the general education program is meaningful and beneficial.

The tone of the book is positive and respectful, stressing the message that *all* children can learn; the trick lies in our ability as educators and support staff to find a way to ensure learning does indeed occur. As the authors note, this often requires a change in attitude from one in which the student is considered to be "too disabled" to benefit, to one in which educators and team members work together to identify and provide the appropriate educational supports. Although this idea of support is not new, what this text does that is especially noteworthy is to provide a multiple of examples that helps the reader to make that important connection between theory and practice.

This book concentrates on the inclusion of students with severe and multiple disabilities and most of the examples focus on students who experience

a significant cognitive delay in addition to a physical and/or sensory impairment. As we know from research, the majority of these students continue to receive educational services within segregated programs (McLesky, Henry, & Hodges, 1999). Although this is partly a manifestation of the longstanding practice of segregation for this group of individuals (Gardner, 1993; Katsiyannis, Yell & Bradley, 2001), not knowing *how* to include these individuals is also a contributing factor. This book directly addresses this issue of *how* to facilitate inclusive education by providing the reader with an abundance of practical strategies and suggestions, not just discussing the importance of providing appropriate supports, but *showing* educators how to implement educational supports in a meaningful way. If the goal is to ensure that all students, regardless of perceived ability, have equal access to inclusive options, then educators must be provided with information on how to make this happen. This text addresses that need.

The text is organized into four sections. The first three chapters serve as an introduction to students with severe and multiple disabilities and provides a rationale for inclusive education for this group of individuals. In these chapters (and throughout the book), the authors remind the reader of the danger of focusing on what the student cannot do, but instead recommend that educators and team members approach each student as an individual who has his or her own set of strengths, as well as unique needs. Understanding what the student can do independently, and what he or she can do with the appropriate supports, is the key to providing a meaningful educational experience.

Chapters 2 and 3 provide a blending of constructivist and behavioral approaches to learning, pulling out the advantages of both approaches and demonstrating how the two learning theories can work together in concert. The constructivist approach to learning is child centered, and stresses that learning occurs within a social context. Individual differences are accepted and each child is encouraged to reach his or her potential. Strategies such as cooperative learning allow for individual differences, and thematic teaching helps students to connect concepts across the curriculum and apply them to everyday life. Thus, the constructivist approach provides the supportive context that helps to facilitate inclusive education. The authors make a good case for the utilization of these approaches and support their arguments with extant research. Unfortunately, not all general education classrooms embrace these strategies, which can serve as a potential barrier to inclusive education. This may require that educators and family members search for the right teacher who is open to modifying instructional strategies to meet the needs of all students.

Although all children benefit from these strategies, some students, especially those with more significant needs, will require systematic instructional strategies to master certain skills. The behavioral approach to learning focuses on identifying specific skills (e.g., through task analysis) and using specific prompting and reinforcement strategies to shape and build new skills. Although these strategies are often linked with special education, the authors very cleverly point out that general educators often use these strategies, although perhaps unknowingly. For example, the authors speak of the teacher who uses a *least-to-most prompting sequence* to help a student spell the word "receive" by first providing an indirect cue—"remember the rule," and, if necessary, uses increasingly more extensive prompts—"remember the rule, i before e," and then, "remember, i before e except after c," and so on, to help the child respond correctly. By providing this and other examples, the authors help to demystify the "special ness" of special education by assisting the reader to understand that the use of these procedures in general education settings is neither unusual nor impractical.

The next four chapters (chapters 4–7) represent the "meat" of this text. In these chapters, the authors provide numerous examples of adaptations for students across the grades, starting with preschool, progressing to elementary and then middle school, and finally ending with high school. The examples also cross disabilities by providing examples of adaptations for students with physical, visual and/or hearing impairments, as well as adaptations for students who experience a significant cognitive delay. What is especially noteworthy about these chapters is the focus on providing an educational program that results in *educational benefit* for the student. It is not enough for students with severe and multiple disabilities to be "placed" in general education classrooms for social reasons. The student is in school presumably to learn, and this includes mastering a host of academic as well as social and behavioral skills. Although social and behavioral needs are addressed throughout the text, the primary focus is on adapting the core curriculum so students with severe and multiple disabilities can access and benefit from this experience.

This second section of the text differs slightly from the first edition in that separate chapters now exist for middle school and high school, providing the reader with additional examples specific to these two school levels. All four chapters stress the importance of assessment, identification of critical skills, and planning to ensure learning goals are realized. The authors also address the importance of planning for the transitions between these grade levels, stressing that each grade level presents its own set of challenges that will require careful consideration and planning. Several strategies are dis-

cussed and reviewed. Given the space limitation, it is not possible to summarize all of the helpful suggestions and ideas presented. Suffice it to say, these chapters represent a great resource for both general and special educators, as well as related and other support staff.

Whereas chapters 4–7 provide specific examples of adaptations, the third section of the book (chapters 8–10) is designed to help team members implement the practices discussed in the previous chapters. Educational planning teams must work together and take advantage of all resources in order to most effectively implement the ideas and practices reviewed. Chapter 8 speaks of the role of peers in inclusive education. Peers provide a natural and rich resource that should be tapped. The authors do a nice job of reviewing the current literature on the use of peer tutors to facilitate inclusive education, which shows benefits for both students with and without disabilities. The reader is appropriately cautioned to make certain peers are given adequate support and guidance so they do not feel overwhelmed, but also to ensure that peers help the student with the disability versus simply doing the task for the student. Also, because students with severe and multiple disabilities are likely to communicate differently (e.g., use of pictures, a communication device, or objects to talk), it is important that adults explain to peers how the child communicates. Chapter 9 speaks of the importance of teaming and collaboration. Working together as a team is an essential component of inclusive education and has been addressed by numerous researchers. This chapter provides an overview of this body of literature. Since students with multiple needs often require the services of several "specialists" (e.g., occupational, speech, vision, hearing, and physical therapists), cooperation and good collaboration among all team members is essential.

Chapter 10 is a new addition to the book and deals specifically with data collection. As the author notes, data collection is often not given the time and attention it deserves. This is problematic for several reasons. First, without accurate data on student performance, it is difficult to discern whether the student is learning. Since students with severe and multiple disabilities are likely to make slow progress, it is especially important that small changes be accurately captured and reflected. Secondly, without data, it is difficult to determine if the teaching strategies being employed are working. Lack of progress signifies a need to alter teaching strategies and/or modify supports. Without pertinent information, these changes may not be made. Finally, the 1997 amendments to the Individuals with Disabilities Education Act (IDEA, 1997) now require that educators clearly demonstrate (e.g., through concrete data) that students with disabilities are making demonstrable progress in meeting educational goals and objectives (Drasgow, Yell & Robinson, 2001).

In their review of published due process court hearings in which school districts lost their case, Drasgow et al. (2001) note that the failure to demonstrate progress was a factor in a number of cases. Thus, the addition of this chapter is not only educationally sound, but also very timely in a legal sense. With the IDEA's increased emphasis on accountability, the need for meaningful data to demonstrate progress will continue. It is imperative that teachers not only acquire data collection skills, but also use these skills on a day-to-day basis.

The fourth and final section of the book (chapter 11 and appendices) provides an appropriate ending to this text. As stated earlier, the purpose of this book is to provide educators, family members and support staff with practical strategies to promote inclusive education for students with severe and multiple needs. Chapter 11 is designed to help the reader find answers to specific questions and/or concerns. The chapter discusses some of the most common questions educators and family members are likely to have regarding how best to support students with severe and multiple needs in inclusive settings. This chapter not only provides the reader with a quick response to a specific question or concern, but also presents a nice summary of the text as well. The appendices at the end of the text give the reader supplementary resources he or she can refer to in order to gain additional information on one or more topics (e.g., augmentative and alternative communication systems, systematic instruction, and inclusion). Although the book is fairly comprehensive, it is not possible to cover everything in the depth that some may wish. The appendices help meet this need.

In summary, this text provides the reader with practical strategies designed to help educators, family members, and support staff promote inclusive options for students with the most significant needs. This text consistently reminds us that *all* children can learn; it is up to us as educators and support staff to figure out how best to support the learning of all students. Furthermore, the educational program must result in *meaningful educational benefit*. This text gives us the tools, ideas and strategies needed to realize this goal.

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Reviewed by
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THE PHYSICIAN'S GUIDE TO CARING FOR CHILDREN WITH DISABILITIES AND CHRONIC CONDITIONS

Robert E. Nickel and Larry W. Desch
2000, Paul H. Brookes Publishing Company
ISBN 1-55766-446-3
$125.00, 800 pages

REVIEW

This excellent resource evolved from a training program for primary care physicians and nurses developed to provide information and materials to help professionals dealing with children with disabilities and chronic conditions.

All the chapters are organized in a uniform way, initially describing some key competencies i.e., issues that the reader will learn from each chapter followed by a description on definitions of the problem, and methods of diagnosis and evaluation and management. At the end of each chapter there are appendices with useful tables and very extensive questionnaires for obtaining an adequate history and physical examination of each of the conditions outlined.

The book starts with defining what disabilities and chronic conditions are, followed by methods for screening and surveillance, nutrition and growth. It then goes into a chapter on general issues such as developmental delay and mental retardation, followed by more specific conditions such as Cerebral Palsy, Attention Deficit Hyperactivity Disorder, Autism, Visual & Hearing Impairments, Anxiety Disorders and Prenatal Drug Exposure.

The last six chapters deal with more specific conditions such as Human Immune Deficiency, Visual and Hearing Impairment, Craniofacial Disorders, Traumatic Brain Injury, Spinal Cord Injury, Seizure Disorders and Chronic Respiratory Disorders.

All in all this is a very comprehensive reference book with up to date information; it is very easy to read by anyone with basic medical knowledge.

The authors have done an excellent job in editing what likely was a syllabus into a book format that is a must for anyone caring for children with disabilities and chronic conditions.

Reviewed by
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INFORMATION FOR AUTHORS

PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES
THE DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

PDERS seeks to publish articles that contribute to the field of knowledge about education and related services for individuals with physical, orthopedic or health impairments. The following are considered for publication: empirical research; theoretical perspectives; case studies which address promising practices; innovative instructional practices; and reviews of relevant books, materials, media and software.

SUBMISSIONS

Manuscripts should be submitted to: Dr. Barbara J. Kulik, 3380 Country Club Drive, Glendale, CA 91208-1718 (bkulik@csun.edu). Three copies of the manuscript, together with a diskette or email attachment of the manuscript in either WordPerfect or MicrosoftWorks in IBM PC-compatible format, should be submitted for review. All tables and figures should be included with each copy of the manuscript.

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The entire manuscript (title page, abstract, text, tables, figures, and references) should be double-spaced on 8 1/2 x 11-inch paper with at least a 1-inch margin on all sides. A cover sheet should include title, author(s) name and affiliation (including statements of credit or research support), address, telephone number and email of the author to whom correspondence should be directed, and a running head. The abstract should precede the text on a separate sheet of paper and should bear the full title of the article. The running head should appear on all subsequent pages.

Tables and figures should be numbered by separate series and placed at the end of the manuscript. Provide brief notes within the text to indicate where each table or figure is to appear.

Overall style should conform to that described in the *Publication Manual of the American Psychological Association*, Fifth Edition, 2001.

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On July 1, I stepped into the DPHD President's shoes (thank you, Steven Daley, for your leadership and vision). It is an honor for me to work on behalf of students with orthopedic, physical, health, severe, or multiple disabilities, the professional that works with them, and you, the members of the Division for Physical and Health Disabilities. Although I am excited about this year, the tasks ahead sometime seem daunting. As Steven outlined in his President's Message last spring (*Physical Disabilities: Education and Related Services*, Volume XX, Number 2, Spring 2002), our speciality, dedicated to serving students with orthopedic, physical, and other health impairments, is facing significant challenges related to OI/OHI teacher training programs, service delivery in regular classrooms, and the role of professional organizations such as CEC. In response to this article, Mary Jane Rapport emphasized the importance of developing a system of teacher training, partnerships, and consultation to serve children with OI/OHI in the regular classroom (*Physical Disabilities: Education and Related Services*, Volume XXI, Number 1, Fall 2002). Dr. Rapport stated that the future of DPHD depends on our ability to attract and retain members who are committed to students with OI/OHI. Although we are small in numbers, we can make a difference in the lives of our students if we stay connected. DPHD is here to help, but we need you! We urge you to:

- Volunteer to serve on DPHD committees. DPHD has three committees that need your participation. **The Critical Issues & Leadership Committee** has been working: encouraging separate certification categories in orthopedic impairments/physical disabilities, exploring methods of providing technical assistance to teachers responsible for instructing students with physical disabilities, and promoting educational aspects of the delivery of specialized health care procedure. Currently the committee constructing fact sheets for dissemination to organizations and on the construction of a national agenda in physical disabilities. The **Severe & Multiple Disabilities Committee** plans to investigate the critical needs of students with severe and multiple disabilities. In addition, this com-

mittee will work with the Critical Issues & Leadership Committee on the national agenda, focusing on students with severe and multiple disabilities. The **Homebound & Hospitalized Committee** is working on policies for instructional services in the home or hospital to children who are hospitalized or homebound. Future activities include sending out a survey to DPHD members about future issues for exploration by this committee and developing inclusionary practices for the homebound/ hospitalized population.

- Propose a high quality presentation for the CEC Convention slots. Share your ideas and expertise about working with students with orthopedic, physical, and other health impairments.
- Come to the Annual CEC Convention and attend the DPHD sponsored sessions, meetings, and events.
- Read and contribute to your DPHD journal *(Physical Disabilities: Education and Related Services)*.

One of the many reasons for a professional journal is to share new scientifically based practices that can be implemented in the classroom. At the recent Division for Early Childhood (DEC) conference, I heard a nationally known scholar state that, as teachers and therapists, we have very little evidence that what we do actually works. How can this be? All of us who have worked with children for many years know what works and what does not, don't we? Unfortunately, there is a gap between what practitioners know works and what has been scientifically studied (or researched).

I am a special educator who holds a faculty appointment in a department of occupational therapy. There is a movement in occupational therapy called Evidence Based Practice (EBP). Simply stated, EBP means integrating individual practical expertise with the best available evidence from systematic research to design effective interventions for children with disabilities. It other words, this means using your judgement and experience to locate those interventions that have been proven to work, and then matching the appropriate intervention to the right child. Teachers and therapists successfully match intervention with students every day. What is missing is the research to support the effectiveness of the intervention. For example, professionals and family members use facilitated communication with amazing results. Other individuals have witnessed first hand the benefits of sensory integration techniques. Parents have reported great gains in their children's development after receiving SI treatment. However, neither of these approaches has extensive systematic literature to scientifically support its effectiveness. While we at DPHD cannot "solve" this lack of scientific evidence, I would like to offer the following proposal.

Many of the officers and committee chairs listed at the beginning of this journal are skilled at searching the available literature and designing solid research studies. Many of the readers of this journal are skilled teachers, using highly effective techniques on a daily basis with their students. Let's get the two groups of folks together! Here is an example of what I am proposing: I am currently working with a person who teaches a yoga class for students with disabilities, ages 7–14 years. This teacher is convinced that yoga has been beneficial for a variety of children with disabilities ranging from mild to significant. However, there is very little literature addressing the use of yoga with children with disabilities. She wanted to determine if participating in her yoga class was effective at meeting specific goals but does not have the time, or interest in conducting a literature review and designing a research study. We joined forces! The literature review and research proposal were developed on my end. The teacher is going to conduct the pretests, teach the class, and conduct the post-tests. She and I will work together to analyze the results. When this is done, we are going to write an article together.

If you have designed an effective intervention that you are excited about and want to test, let us know. One of the officers and/or committee chairs can work with you to design a study to test the effectiveness of this intervention. Please email me at *dlowman@mail2.vcu.edu*, describe the intervention you want to test, and I will put you in contact with the appropriate officer or committee chair.

Thank you for all the work you do on behalf of our children and families. Remember that DPHD is here to help you do even more. I hope to see you in Seattle.

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GUEST PRESENTATION
SOMEONE WAS WATCHING OVER?

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Court Appointed Special Advocate
Los Angeles, California

The Dependency Court, a division of the Los Angeles County Superior Court, hears cases involving issues of child neglect and abuse. The court has responsibility for ensuring that all children under its jurisdiction receive appropriate care and services in the foster care system. The Department of Children and Family Services is the primary government agency charged with the responsibility of providing the children with needed care and services. With over 30,000 children under the court's jurisdiction, and every Children's Social Worker (CSW) carrying caseloads of 50 to 60 children, each child receives limited attention. To help these children, and to assist the court in meeting its responsibilities to the children, the Superior Court founded the Child Advocates Office, a program comprised of a supervisory professional staff and volunteer Court Appointed Special Advocates (CASA).

CASA volunteers are appointed by judges to the cases of specific children. The role of the CASA is to gather comprehensive information about a child's needs and circumstances, report findings and make recommendations to the judge, monitor compliance of the court's orders, facilitate the provision of needed services, and advocate in court and in the community for the best interests of the individual child. A CASA usually carries one or two cases at a time, depending on a volunteer's time availability. Since there are currently only about 300 CASA volunteers in the program, compared to over 30,000 children under the court's jurisdiction, only the most needy children have a CASA assigned to them.

This particular case is one in which, when the CASA received it, it involved three brothers, Anthony, age 6, Carmen, age 5, and Pedro, age 4. When Pedro was born, he and his mother both tested positive for cocaine, and Carmen had earlier tested positive at his birth for cocaine. Their father had a history of substance abuse and that rendered him incapable of providing regular care for the family. A neighbor reported to DCFS that the chil-

dren were being neglected, and the children were declared dependents of the court and placed in foster homes. Family reunification was ordered by the court. The mother and father were ordered to complete parenting education, participate in substance abuse counseling and random drug testing, and individual counseling to include anger management and domestic violence. The boys' father abandoned the family and did not participate in the court-ordered activities.

After one year, Anthony was allowed a 60-day visit with his mother, since she had successfully completed the court's requirements. In succeeding months, the other boys also joined their mother, and the court terminated its jurisdiction in the case a few months later.

About two years later, the boys' mother left the boys in the care of a neighbor, saying she would return shortly. After a number of days when the mother did not return, the neighbor reported to the DCFS that the boys had been neglected and/or abandoned. The children were immediately placed in foster care. At the very first court hearing, the judge requested that a CASA be assigned to the case, and I was given the opportunity to take the case, which I did. The guidance given me was that the children's spoken language was unclear and that their needs included physical and dental exams, as well as psychotherapy.

Upon visiting the foster mother and the children a few weeks after the boys were placed there, it was apparent that they all were Hispanic. However, the children's language was not Spanish or any other language I could detect. It was unstructured and presented in only two or three word sentences, but it seemed to be something the children understood between them. The foster mother spoke in broken English with me, and spoke to the boys in Spanish. One of my immediate goals was to get the boys in an English-speaking mode, and I requested the foster mother to only speak to them in English as I would arrange for speech therapy for them. She agreed and said her husband would as well.

While there, the foster mother showed me evidence of the boys having been seen by a doctor and dentist she had taken them to who both recorded that their health was good. She also indicated the name of the psychotherapist in the area that the boys were seeing. She said that the two older boys, Anthony and Carmen, were just started in school, their first school experience. Anthony was placed in the first grade and Carmen was attending kindergarten. She said that Pedro was too young for school and was staying in the house watching TV or playing with toys while the other boys were in school because there were no kids his age in the immediate neighborhood. It

was apparent while visiting the home that the two older boys played together, while Pedro had to occupy himself.

After that first visit, and with the guidance initially provided me by the court and Child Advocates Office, my priorities were to get the boys speech therapy, get Pedro placed in some type of pre-school program so he could interact with children his own age, and get all of them psychotherapy that would address the loss of their mother's presence. After inquiring at the Los Angeles Unified School District how I could accomplish these goals, I first met with the school's psychologist and filled out a number of forms requesting an Individualized Education Program (IEP) meeting to request speech therapy for the two older boys as a special education requirement, and requested preschool for Pedro. Subsequently, a separate IEP meeting took place for each of the older boys, at which times I made a case for speech therapy, and it was approved. At another IEP meeting for Pedro, I made the case with the School District's special education personnel that Pedro needed a preschool environment to expedite his assimilation into the company of other children his own age, as well as his need for speech therapy. That also was rapidly approved by the school district, and Pedro immediately started preschool on the same property as the older boys' school.

Although speech therapy had been approved for all three boys, the school informed me that the school's speech therapist was already overbooked and could not take any more cases. The speech therapy office at the school district advised me that there were no other speech therapists available in the district. I petitioned the school district to authorize an outside speech therapist and they provided me with a short list of approved therapists. I contacted a number of them and finally found one that agreed to go to the children's respective schools to provide the speech therapy authorized by the school district.

I made it a habit to visit the boys every two or three weeks, reading to each of them, leaving the books, giving them gifts offered by the Child Advocates Office, talking about their school progress, and generally being a friend of theirs. That was pretty easy because all three boys were very responsive. Also, after a few weeks of school, I visited with each of their teachers and asked about their progress. They all indicated that it was a slow process because each of them had not been in school before, but the boys were coming along well. I asked if the two older boys would benefit from home tutoring and they said yes. When I inquired of the CSW how I might arrange for a tutor for Anthony and Carmen, she said we would have to put in a request and that would have to be processed, followed by selecting a tutor from an approved list. I suggested that because of the boys' young age, a qualified high

school senior at much less cost would seem to be more than adequate for the tutoring job. However, the CSW said that DCFS would only reimburse the cost if their approved tutor was used. My conclusion was that time was of the essence and a high school student would suffice. I went to the local high school and, through the office of student post school assistance, interviewed two recommended seniors and selected one of them as the tutor; she was the class valedictorian. The Friends of Child Advocates, a non-profit organization tied to the Child Advocates Office, funded the nominal cost of tri-weekly tutoring that the young tutor provided after school at the foster home. She was guided by suggested materials the teachers sent home with the boys. The boys rapidly improved in speaking English and in their schooling as a result of the special attention they were given at school and by the tutor.

A couple of months later, I was informed by the children's CSW, who incidentally was very supportive of my efforts in meeting some of the children's needs, that the foster mother had just been accused of molesting or abusing a child in a prior case, and that the children had been immediately removed and placed in another foster home as a precaution. Unfortunately, the new foster home was located far from the earlier home and thus required a new school and preschool. In addition, the prior speech therapist refused to travel to the new location because of its distance from his base location. As a result, I solicited another of the approved therapists and she agreed to provide those services at the boys' foster home. Further, the tutor was unable to travel to the new location, so her services had to be terminated.

The new foster parents were extremely competent and helpful. They had an excellent home setup for foster care of young children, complete with a great many storybooks, games and toys, all located in a very large playroom. It was no surprise that the boys adjusted rapidly to their new surroundings. After my transferring a copy of all the IEP meeting reports to the new elementary school and nearby preschool, and to the foster parents, the parents immediately made arrangements with the schools for the boys to continue in school with minimum delay. The schools said that tutoring would be provided by the school if needed. A local psychotherapist was also arranged for, by the foster care agency under which the foster home was licensed, to provide services at the home.

As before, I visited the boys in their new environment every few weeks, again reading to them and bringing gifts provided by the Child Advocates Office. It was gratifying to see the improvement in their speech, the ability now of the two older boys to read, and to listen to the excitement by all three boys of things going on in their lives at school and in the other activities that the foster parents had provided.

After about 6 months of foster care, and because the boys were considered by the court to be adoptable, the CSW took the boys to an adoption fair where a number of available children under the court's jurisdiction were taken to give prospective adoptive parents an opportunity to consider adoption candidates. I had attended a seminar on adoption processes at which it was noted that the likelihood of two siblings being adopted by the same family was not particularly high, and that the likelihood of three siblings being adopted by the same family was remote. I shared those concerns with the CSW, especially since all three boys were so bonded to each other. However, we agreed that being adopted separately would be better for the boys than long-term foster care, and that they would still be able to visit with each other occasionally.

At that particular adoption fair, an adoption agency representative visited with the boys and took a fond liking to them. She said she knew prospective adoptive parents that she would like to meet the boys. Such a meeting was arranged and the children and prospective parents connected immediately. The wife was a middle aged retired teacher, having taught kindergarten through 4th grade. The husband was the manager of a major bank branch. They had no children of their own and lived in another California city. After a couple of meetings with the boys, they expressed great interest in adopting the boys, and adoption proceedings were initiated. Oh yes, the prospective parents had 4 boarded horses, two dogs, and a pet pig. Needless to say, the boys were delighted from the very start of the association, and during trial periods of stay at the parent's home they particularly enjoyed the company of the dogs and pig, and especially enjoyed riding the horses. I took the opportunity to visit the prospective adoptive parents and boys early on and was pleased with what I saw in terms of the togetherness there.

As the case moved towards adoption, the boys' birth mother somehow learned of the pending adoption, presumably from the formal public notice and/or publication regarding the adoption. Up to this point, the court had been unable to contact her, and she had not attempted to contact the court. She petitioned the court for custody of her boys, interrupting the adoption process for a time. However, the court denied her request based on the evidence of her past and current situation, and determined that the boys would be much better off with the prospective parents. Subsequently, the adoption was completed.

These three boys may be some of the luckiest in the world. The odds of all three being adopted in the same qualified, devoted and stable family is miniscule. Somebody must have been watching over them!

As in each of my CASA cases, I felt very rewarded in that I helped in some way to better the life of a child. It has convinced me that there is a very important role that we as CASAs can fill. There are CASA programs throughout the country. If you are interested in participating in CASA activities in your area, please contact the National CASA Association at (800) 628-3233.

Address correspondence to Harold Perla at perla27@earthlink.net, or The Superior Court, Child Advocates Office, 201 Centre Plaza Drive, Suite 3, Monterey Park, CA 91754-2158

SELF-REGULATORY STRATEGY USE OF CHILDREN WITH CANCER IN AN ALTERNATIVE EDUCATION SETTING

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ABSTRACT

Drawn from a qualitative multiple case study, this article focuses on the extent to which academic self-regulatory strategies are effectively used by children with cancer in a non-conventional, authentic learning setting. According to Zimmerman, Bandura, and Martinez-Pons (1992), no educational environment can ensure learning. Academic self-regulation encourages students to be proactive regulators of their own learning processes. The degree to which students perceive themselves to be efficacious participants in the learning process will positively contribute to their level of success, to their sense of competency and autonomy, and to their more general self-efficacy beliefs and overall well-being. In this study, attention was devoted to the students' organization and planning strategies, goal setting, environment structuring, ability to seek social assistance, task orientation, and study and work habits.

As an increasing number of children are living with cancer, more emphasis is being placed on minimizing its effects on child development. The care associated with cancer treatment now focuses not only on physical requirements, but on the whole child (Health Canada, 1996; Moffitt, 1985). Because of this holistic approach, the role of school becomes critically important during cancer treatment. Through the school experience health impaired children have the opportunity to learn, to develop a sense of independence and self, and to experience success despite the imposing limitations.

Bandura (1993) suggested that self-regulatory processes govern human development and adaptation and that effective intellectual functioning, in particular, requires more than understanding factual knowledge, but the exercise of human agency. Zimmerman (1986) further argued that self-regulated learning constitutes a new approach to the study of student academic achievement. In contrast to traditional measures, the self-regulatory construct focuses on how students become metacognitive, motivational, and behavioural promoters of their academic achievement within specific contexts. Ultimately, the effective use of self-regulatory strategies is theorized to enhance student perceptions of control, autonomy, competence, and self-efficacy (Zimmerman, 1986). Therefore, based on Bandura's (1986) self-efficacy construct embedded in social cognitive theory and Zimmerman's approach to self-regulated learning, this research addresses aspects of hospital teaching and the academic learning experiences of students with cancer. More specifically, this paper explores the children's academic self-regulatory strategy use while in the non-conventional educational setting of the hospital.

Although elements of a Canadian hospital education program will be discussed, this paper will not be limited to an analysis of a board specific program, but will focus on a theoretical framework. However, before discussing this theoretical component and the research findings, it is first necessary to provide some pertinent information concerning (a) one hospital education program operating in Eastern Ontario, (b) the death and occurrence rates of childhood cancer in Canada, (c) the effects of health impairments and hospitalization on child development and academic achievement, (d) barriers typically associated with providing educational services to health impaired children, and (e) the influence of control beliefs on successful learning.

BACKGROUND INFORMATION AND LITERATURE REVIEW

Hospital Education

The hospital education program in Ontario is the responsibility of the board of education and the care and/or treatment facility in which it is located. It provides educational services for children who for medical reasons cannot attend school. The intent of this program is to ensure that the student maintains academic progress so that the child's reintegration into school may be facilitated. This is a valuable educational service as it provides students with

educational continuity and an opportunity to exert influence and experience success.

Unfortunately, there is little research in the area of hospital instruction and educational services for children with health impairments. The lack of scholarly attention may be due to program variability across school boards. However, some American sources do note the phenomenon of an increasing population of health-impaired children and the demands these students have placed on the education system.

Chronic Health Impairment

According to Lynch, Lewis, and Murphy (1992, 1993), between mid-1960 and mid 1980, the number of children with a medical condition doubled. Currently, it is estimated that between 10 and 20 million American children and adolescents have some form of chronic health impairment (Bunke & Schwanz, 1997). Many researchers attributed this increase to improvements in technology and medicine that have allowed children who would have previously died to survive with medical assistance (Cunningham, Lockwood, & Cunningham, 1991; Johnson, Lubker, & Fowler, 1988; Mabe, Riley, & Treiber, 1987; Ross, 1984). Similar progress in the treatment of childhood cancer has meant that what was once considered an acutely fatal disease is now considered a life threatening chronic illness (Mabe et al., 1987).

Chronic health conditions have been defined as being any medical condition that (a) interferes with daily functioning for more than three months in a year, (b) causes hospitalization lasting more than one month in a year, or (c) is thought at the time of diagnosis to result in either of the preceding (Bunke & Schwanz, 1997). Because of these constraints, chronically ill children require alternate types of instruction for potentially long periods of time. Consequently, these medical conditions may have a significant effect on the children's lives.

A sense of the number and types of children who may benefit from a hospital education program can be obtained by exploring the occurrence rates and characteristics of the different chronic conditions. For this study, the occurrence and mortality rates associated with childhood cancers in Canada are of particular interest.

According to the National Cancer Institute (1999), for the period between 1990 and 1996, an average of 879 children, aged 0–14 years, were diagnosed each year with some form of cancer and 176 deaths resulted from the disease. Health Canada (1996), however, suggested that when children and teenagers are considered, approximately 1300 to 1400 are diagnosed with cancer each year and that approximately 10,000 Canadian children already

live with a form of cancer and its long-term effects. From a historical perspective, both sources indicated a declining trend in the number of deaths and an increase in the number of occurrences. Although each form of cancer has a different survival rate, Health Canada (1996) noted that "over 70 percent of Canadian children and teenagers diagnosed with cancer between 1985 and 1988 were alive five years after diagnosis" (p. 25).

Influence of Health Impairments on Child Development and Achievement

Once cancer has been detected, the physical effects that result from the appearance and the necessary treatment represent only one of the ways in which children are affected by their condition. Unfortunately, health impairments interfere with all aspects of normal child development. Perrin and Gerrity (1984) effectively illustrated how the development of children with health impairments may be understood within the context of the cognitive, social, and emotional development in all children. They suggested that the process of development depends on children's interactions with their environment. As a result of children interacting with and influencing their environment, the environment changes and in turn these environmental changes affect the children. Environments, according to Zimmerman (1995), are "assumed to be just as sensitive to people as the reverse, and both are in constant change" (p. 369). The mechanisms by which children's chronic illness may modify their development can be viewed in the same manner; the illness affects the children's interactions with the environment in which they live and aspects of that environment are altered as a result of the illness. Therefore, the implications of long-term health impairments on children's social, emotional, and cognitive development may be considerable.

Zimmerman (1995) suggested that cognition, in particular, is inextricably linked to the context and cannot be understood apart from it. Thus, at the heart of normal child development is the interactive context of the learning experience. Once children are able to plan and adjust their personal, behavioural, and environmental functioning in response to their changing conditions, they will have developed self-regulatory competence and this self-regulatory development can affect the learner's choice and response to a variety of changing social and personal experiences.

If Zimmerman's position is accepted that cognitive development is dependent on contextual factors, then the questions requiring further exploration in the research literature include: (a) How do chronic conditions

affect children's learning and academic achievement? And, subsequently, (b) What are the effects of hospitalization on children and their learning?

Research findings indicated that learning difficulties might result from cancer treatment in young children two to five years after diagnosis (Armstrong & Horn, 1995; Findeisen & Barber, 1997; Moffitt, 1987). However, despite this possible effect, Sexson and Madan-Swain (1993) suggested that children with any form of chronic illness often experience academic difficulties and fail to achieve their potential in comparison with their healthy peers. Due to the sporadic nature of some health impairments, prolonged absences or multiple brief absences from school may result in a discontinuity in the educational program and uncompleted schoolwork. Educational deficits are most likely to appear in school subjects that build on previous work (Sexson & Madan-Swain, 1993). Schunk (1985) suggested that students who do not possess intellectual deficits but perform below their measured abilities may experience repeated difficulties resulting in academic deficiencies which then interfere with general self-functioning and a student's sense of efficacy for coping with cognitive demands.

Sirvis (1988) stated that medical concerns are major factors affecting learning for chronically ill students: "Fatigue, limited vitality, short attention span, and limited mobility are just some of the characteristics that can accompany technological and medical dependence" (p. 42). However, despite these limitations, Moffitt (1987) warned teachers and parents not to underestimate a child's potential or to lower their expectations for achievement. Chronically ill children will interpret these feelings as a lack of faith in their future and may respond with feelings of helplessness, discouragement, and sometimes anger.

Necessarily, a child with cancer will spend time in the hospital and the pain and discomfort that accompanies the condition and/or treatment may leave the child feeling vulnerable. Hospitalization places children in unfamiliar surroundings and separates them from family members for prolonged periods of time. Procedures and treatments are disruptive, painful, and intrusive. These experiences may result in feelings of fear, anxiety, and a lack of control over their lives, bodies, and even daily routines. Hospital teachers need to be sensitive to the realization that the children are in a non-conventional education setting and that the medical treatments necessarily take precedence over educational programming. But, at the same time, the achievement of educational goals must be an important objective (Kleinberg, 1982; Unsworth & Howard, 1994). By working cooperatively with medical personnel, obstacles typically associated with providing education in alternative settings may be overcome.

In their 1992 study, Lynch et al. attempted to identify the schools' and families' perceptions of the needs of children with chronic illnesses to suggest ways to ameliorate the academic services provided to this group of students. Their findings illustrated that many chronically ill children did not have Individualized Education Programs (IEP) and that there was a lack of funding, training, organization, and personnel within the system. Armstrong and Horn (1995), Lehr (1990), and Quinn (1987) suggested that children with cancer require unique educational plans particularly as childhood cancer and its treatment can present multiple school-related problems. Some of these problems may be of short duration while others may be long-term difficulties requiring on-going assessment, monitoring, and intervention. Additionally, cancer can be particularly complex and the difficulties children experience as a result may vary with the child, the cancer type, and the treatment requirements. If educators are uninformed and cannot respond effectively to the student's condition and school needs, the teacher's discomfort and education problems are likely to be significant (Chesler & Barbarin, 1986).

According to Baken (1978), successful learning is dependent, at least in part, on whether individuals perceive that they can control the contingency between behaviour and reward. Since the restraints of being ill affect such perceptions, Baken compared three groups of children (emotionally disturbed, physically disabled, and health impaired) receiving educational services at home with respect to locus of control beliefs. Although self-efficacy beliefs and locus of control perceptions are not synonymous, the influence of control beliefs on successful learning is common to both. Baken concluded that provisions for more meaningful educational services could be achieved if teachers used the child's locus of control perceptions to the child's advantage. By examining the student's perceptions of control, whether it is through an examination of locus of control or through the narrower construct of self-efficacy beliefs, teachers can structure the educational experience in such a way as to enhance academic progress and promote normal child development.

PURPOSE OF STUDY

Consequently, the paper's major research question is as follows: To what extent are academic self-regulatory strategies effectively used in a non traditional educational setting by this specialized group of students?

THEORETICAL FRAMEWORK

According to Bandura (1995), the issue of control is central in human lives and is especially important for those individuals who feel powerless to exert influence over events in their lives. Among the control mechanisms people use, none is more critical than people's self-efficacy beliefs (Bandura, 1995). Perceived self-efficacy refers to "beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (p. 2). Thus, personal efficacy beliefs influence how people think, feel, motivate themselves, and act.

Zimmerman (1995) built on Bandura's work and further suggested that there is a mediational role of perceived self-efficacy on children's educational development seen through processes of self-regulation. Since no educational environment can ensure learning, "academic self-regulation is concerned with the degree to which students are . . . proactive regulators of their own learning process" (Zimmerman, Bandura, & Martinez-Pons, 1992, p. 664). The degree to which students perceive themselves to be efficacious participants in the learning process will positively contribute to their level of success, to their sense of competency and autonomy, and to their more general self-efficacy beliefs and overall adjustment. Thus, self-regulated learners should be able to direct their learning experience by enlisting self-regulative influences that will motivate and guide their academic pursuits (Zimmerman et al., 1992). Zimmerman and Martinez-Pons (1990) identified 14 categories of self-regulated learning strategies used by students in classroom and non-classroom settings. These strategies include organizing and transforming, rehearsing and memorizing, goal setting and planning, self-evaluating, self-consequating, information seeking, record keeping, self-monitoring, environment structuring, seeking social assistance, and reviewing academic materials. In this study, particular attention was devoted to the students' organization and planning strategies, goal setting, environment structuring, ability to seek social assistance, task orientation, and study and work habits.

METHODS

To understand the extent to which self-regulatory strategies are used by students with cancer in the hospital setting, the cases of hospitalized children were explored. The data for this research were collected using multiple measures over a three month period. The philosophical assumptions underlying this case study are qualitative rather than quantitative in nature with an

emphasis on describing and interpreting the phenomenon within the context.

Participants

The cases focused on the learning experiences of five hospitalized students with cancer (two girls, three boys), ranging in age from 9 to 13 years, receiving educational services in one large Ontario children's hospital. The educational services provided consisted of 30 minutes per day of individual teacher-led instruction, in the compulsory subjects, while the child was in the hospital either due to an admittance or as an out-patient. These services are meant to either supplement the children's already existing school or home program, or could be the children's only source of educational services.

The scope of the study was limited to an examination of the children's hospital learning experiences and to those people directly involved with the children's hospital education. Thus, in addition to the five children, the study included three hospital teachers, one home instruction teacher, and the five students' mothers making a total of 14 participants. Informed consent was obtained from all participants and confidentiality has been ensured through the use of pseudonyms (see Table 1 and 2 for participant information). These pseudonyms will be used when referring to study participants.

Research Design

The research design consisted of the following data collection methods: participant observations, semi-structured interviews, document reviews, and participant activity sessions. As was expected, the participant observations and interviews were the primary sources of data collection. However, each method will be described in more detail.

First, participant observations were collected at least three times per child during the students' individualized classes with the hospital teachers. The observations focused on the setting, the participants involved, the students' use of self-regulatory strategies, the activities and interactions, the frequency and duration of the sessions, and subtle factors such as non-verbal communication. All observations were recorded as field notes.

Second, semi-structured interviews took place once with each participant. These interviews adhered to a prescribed set of open-ended questions that varied only slightly depending on whether the interview was with a student, a mother, or a teacher. The interviews were audio taped and transcribed and focused on the students' use of self-regulatory skills, their social interactions, and their satisfaction with their school experience. Adult participants

TABLE 1
Student Participants

Pseudonyms	Gender (M/F)	Age in years	Grade	Diagnosis
Steven Smith	M	9	4	Neuroblastoma
Alex Walters	M	11	6	Neuroblastoma
David Wilson	M	11	6	Osteo Sarcoma
Amanda Johnston	F	9	3	Acute Lymphoblastic Leukemia
Jill Perron	F	13	9	Osteo Sarcoma

TABLE 2
Adult Participants

Pseudonyms	Participant Type
Evelyn Richards	Home teacher for Steven
Julie Simms	Hospital teacher for Alex & Amanda
Cathy Adams	Hospital teacher for Steven
Cheryl Jones	Hospital teacher for Jill & David
Mrs. Smith	Mother of Steven
Mrs. Walters	Mother of Alex
Mrs. McDonald	Mother of David (married to David's step-father)
Mrs. Johnston	Mother of Amanda
Mrs. Perron	Mother of Jill

were also given the opportunity to review their transcripts and to make any necessary changes.

Third, because personal documents can be reliable sources of data concerning a person's beliefs and attitudes, the student participants completed journal entries at the end of three hospital education sessions during which observations were recorded. To complete these entries, the children answered a set of prepared questions regarding themselves as learners and how they felt about their learning experiences in the hospital setting. These entries allowed for verification of the accuracy of the observations and to understand better the different perspectives of the individuals involved.

A review of the children's report cards and their Ontario School Records was also conducted. Reviewing these documents allowed the children's academic histories to be traced and to obtain a more global picture of the students' school experiences. Interestingly, in all but one of the children's cases, there was no record in their school files for periods of time coinciding with academic terms during which the children received education either in the hospital alone or in combination with a board supplied home instruction teacher.

Finally, each student met with the author individually on three separate occasions to complete educational activities. She participated with the students in completing a naturalistic exercise and, in so doing, observed how the students activated and sustained cognitions, behaviours, and affects that allowed them to complete an assignment or goal. Impressions and observations during these activity sessions were recorded as field notes immediately following the session completion.

Analysis

Data management and analysis are believed to "occur before data collection, during study design and planning; during data collection as interim and early analysis are carried out; and after data collection as final products are approached and completed" (Huberman & Miles, 1994, p. 429). Data reduction, therefore, begins at the outset of the research with a proposed study design and continues throughout the research process. Decisions made concerning the theoretical framework, research questions, instrumentation, changes to the instrumentation, and the "case" definition itself all involve anticipatory data reduction (Huberman & Miles, 1994). In making these decisions, the researcher focuses the research and calls attention to particular aspects for investigation. Like all qualitative methods, this method of data analysis aims to describe and explain a pattern or phenomenon using a set of conceptually specified categories and themes. From these categories, codes can be applied to the raw data. According to Lofland and Lofland (1995), coding is the "most basic, continuing, concrete and mundane way one works at developing analysis" (p. 186).

The analytical categories for this study were established from the research literature and focused on how self-efficacy beliefs influence the following processes: (a) student motivation, (b) student cognition, (c) student affect, and (d) student adjustment under adverse conditions. These broad categories were further subdivided into more specific units of analysis and were coded and recorded. From this coded data, a narrative describing each child's case was written. This paper will highlight the results as they relate to the analytical category of *student cognition* with particular attention to the students' use of academic self-regulatory skills such as organization and planning, goal setting, environment structuring, seeking social assistance, task orientation, and study and work abilities.

RESULTS

A challenge for any theory emphasizing socialization, is to explain how control of behaviour and learning can be managed by the individual (Grusec, 1992). Bandura (1997) believed that this is possible through self-regulation. According to Bandura, people develop domain-specific beliefs about their abilities that not only guide their behaviour, but also determine what they will try to achieve, how much effort they will put into a particular situation, and how long they will persist even in the face of difficulties. For Zimmerman (1989), in order for students to qualify as self-regulated learners, they must

make use of specified strategies which assist to regulate their personal functioning, academic performance, and learning environment, and allow the student to achieve academic goals on the basis of their self-efficacy perceptions. Thus, as mentioned above, particular attention was devoted to the students' use of regulatory strategies involving organization and planning, goal setting, study and work habits, environment structuring and task orientation, and seeking social assistance. Following is a more detailed discussion of these strategies.

Organization and Planning

None of the children in this study planned or organized themselves in preparation for school or for their hospital education sessions. Although four of the children occasionally indicated what topics they wanted to cover during their education sessions, most of the organization and planning was undertaken by the children's teachers and mothers. Although Jill did have a system of using notes in her binder to remind herself of areas in which she required assistance and should be discussed with the hospital teacher, she still indicated, in her interview, that her mother was involved in structuring her educational experience. One mother and one hospital teacher believed that the organization and planning involved in the children's educational program should not be the children's concern particularly if the children are at the elementary school level. Hence, very few school related expectations were placed on the children by the hospital teachers. One child believed that his responsibilities were simply to get himself to the hospital, undergo his treatment, and to do his assigned work. In his opinion, any other school related issue should be addressed by his mother and teacher. Cathy, a hospital teacher, indicated that the mothers become involved in the children's educational programming as a coping mechanism. She stated, "I've seen a lot of parents get very involved in education because it gives the parents something to do. They are lost. They are trying to cope." By becoming involved in this manner, the mothers were able to positively focus their energies on something other than their child's illness.

Because the mothers assumed much of the education coordination responsibilities, they often acted as a liaison between the community school and the hospital program. In all five of the children's cases, the mothers physically transported the children's schoolwork back and forth between the school and the hospital. This was done so that the children's completed work could be assessed by the classroom teacher and so that educational materials were available for the children's hospital education sessions. However, this responsibility was often burdensome for the mothers. Mrs. Perron, for exam-

ple, explained that as a concerned parent, "The only way to keep up while you are going through this is to be really organized and you have to chase down the teachers and work and even then it is very difficult." Consequently, the mothers believed that more coordination responsibility should be assumed by the teachers involved in the children's cases.

Goal Setting

Although formalized proximal goal setting by the teachers, mothers, or students while in the hospital was not observed, it became evident that distal general goals such as receiving good marks, keeping pace with peers, and returning to the school setting were very important to the children and mothers. Jill clearly articulated these goals and sentiments when she stated, "I want to keep up with the work and I want to get a good grade and keep improving." It was speculated that this lack of systematic goal setting might be attributed to the lack of clear expectations found in the children's hospital education programs. Although the hospital teachers did encourage the students to use some learning strategies for certain tasks, specific and proximal goals can only be set when there are clear educational objectives or when each child has the benefit of an individualized education plan. The observations showed that the development of individual educational plans was not taking place.

Study and Work Habits

Although all of the children believed they were capable of studying and working in the hospital setting, their ability to do so seemed to be determined by two factors (a) how they were feeling on a given day, and (b) to what extent they were distracted by the environment. As will be discussed in the forthcoming section, the hospital was considered to be an especially poor work environment. Two students, in particular, believed that their educational experience could be improved if the hospital teachers were provided with school supplies and if there was a more appropriate workspace with fewer interruptions.

Environment Structuring and Task Orientation

According to Zimmerman (1989), a student's ability to be a self-regulated learner will be influenced by the structure of the learning context, particularly such aspects as the academic task and the setting. Therefore, changing the difficulty of an academic task or changing the setting from a noisy to quiet place is expected to affect self-regulated learning and a student's self-efficacy perceptions. Effective self-regulated learners will thus use strategies

such as environment structuring or seeking teacher assistance to improve the environmental influences surrounding their learning, thereby increasing the likelihood of achieving academic success and positively affecting their efficacy beliefs.

In this study, the content difficulty and appeal, as well as the context in which the learning took place did affect the children's efficacy beliefs. All the participants agreed that the hospital is a difficult learning environment as it is not designed to be an educational institution. During the study, it was observed that instruction was provided wherever there was space such as in the students' rooms, in the hospital corridors, or in the play areas located on the hospital floors. Consequently, there were very few opportunities to optimize the learning environment. However, even when there was an opportunity to improve the educational context, this structuring was not done by the students. For example, it was consistently the children's mothers or teachers who would ensure that the television or computer game was turned off and that the children were suitably arranged in their beds in preparation for their education sessions. All of the children commented on preferring to complete their homework at home.

Although the children believed they had the ability to remain task focused, Jill and Alex explained that, from their perspectives, it is more difficult in the hospital than in school because as Jill stated, "they are totally different distractions." Jill, David, and Alex all commented that they enjoyed the school atmosphere. More specifically, they enjoyed having their peers around for the purposes of social comparisons, for collaboration, and for social interaction. However, according to Jill and Alex, because their classmates are also their friends and peers, they are able to disregard them as potential distracters. For example, Jill stated, "At school, there are people who are trying to bug you, but here, they are either trying to help you or they are . . . not trying to deliberately distract you . . . and you don't want to ignore them." From Jill's perspective, because she did not want to be rude to her health care providers, she did not believe she could effectively control or structure her hospital learning environment. Additionally, Alex missed the structure of the classroom, with desks and other learning materials, and thus found the hospital to be a more difficult learning environment.

Seeking Social Assistance

Despite the limitations inherent in the environment, it was believed that all the children benefited from the individual hospital teacher attention. Those students who had a history of being easily distracted in the classroom setting, were retaining more of their lessons than they realized because of the indi-

vidual teacher contact. All of the children readily interacted with their hospital teachers and did not hesitate to seek their assistance.

DISCUSSION

According to Zimmerman (1989), to be a self-regulated and highly efficacious learner, students must be able to "personally initiate and direct their own efforts to acquire knowledge and skill rather than relying on teachers, parents, or other agents of instruction" (p. 329). Although it is inaccurate to describe a person as un-self-regulated, because every person must regulate personal functioning in some way, according to Zimmerman's definition, these students are not effective self-regulated learners within the hospital context (Winne, 1997; Zimmerman, 2000). In some respects, these children seem to be so highly managed by their mothers and teachers, while in this unique environment, that they do not need to exercise self-regulatory skills. If effective self-regulatory strategy use does indeed result in feelings of academic competence and efficacy, why then, did at least four of these hospitalized children still state feeling academically successful in the hospital environment? These children are made to feel successful and academically efficacious through the positive reinforcement they receive from their teachers and mothers. In addition, because these children believe that their mothers and teachers are working in their best interests, it seems that they can be dependent on adults to regulate and structure their learning experiences without having this dependency affect their individual academic efficacy perceptions.

Bandura (1997) suggested that parental influences contribute to the scholastic attainments of children in several ways. Parents provide resources, guidance, modeling, and other incentives that promote learning. In these cases, the mothers and hospital teachers optimized the children's learning experiences as much as possible. The children, in turn, did not hesitate to seek adult assistance when required. However, allowing chronically ill children greater opportunity to control and have responsibility of manageable aspects in their lives may be more beneficial to their overall well-being and psychosocial adjustment. The amount of responsibility a child could assume would of course be dependent on the individual child and his or her physical condition. Although some learning strategies were introduced to the children during the time of this study, for children to become self-regulated learners, they must be consistently taught and modeled a variety of different self-regulatory skills. The use of these skills may indeed allow students with

cancer to become autonomous learners and may have positive repercussions not only in the area of academics, but on their overall efficacy beliefs.

Study Limitations

Although case study methodology is considered to be a powerful way to gain insight into educational issues, through understanding the experiences and perceptions of the individuals involved, there are limitations involved with this type of research and specific to this study. First, the investigator and the inquiry are inextricably linked. Ultimately, the investigator must shape the narratives and information given by the participants and this shaping of a new construction is limited.

This study also represents a preliminary investigation into an area of hospital teaching and educational psychology and is not medical research. As such, this study did not explore ways in which the disease of cancer or cancer treatments affect learning and cognitive functioning.

With respect to participant sampling, this study included five hospitalized students and the adults directly involved in the students' hospital education. This smaller sample size was essential as an in-depth understanding of the children's cases as well as the hospital as a learning environment was required. Fathers and members of the children's extended family were not included in the study.

In addition, the methods used investigated student self-regulatory strategy use in the hospital setting only and primarily focused on obtaining data during the hospital education sessions when the children were interacting with the adult participants. Evidence of self-regulatory strategy use may be more pronounced when the children are alone or in a classroom setting.

Study Contributions

Despite the study limitations, this research contributes to theory and extends our knowledge. Not only is it the first study to investigate self-regulatory strategy use and self-efficacy beliefs in chronically ill children under adverse conditions, but it also explores the following research question: To what extent are academic self-regulatory strategies effectively used in a non traditional educational setting by a specialized group of students? According to Zimmerman's (1989) definition of self-regulated learning, the students in this study were not effective self-regulated learners. Ertmer, Newby, & MacDougall (1996) suggested that self-regulation skills foster learning from any instructional method within conventional settings, but few investigations have been conducted to determine whether these strategies apply across instructional contexts. Further study is therefore required to investigate

which regulatory strategies best promote learning in non-conventional academic settings, authentic learning situations, and/or under adverse conditions.

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SERVICE DELIVERY PRACTICES AND EDUCATIONAL OUTCOMES OF THE RELATED SERVICE OF OCCUPATIONAL THERAPY

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ABSTRACT

"Service delivery practices" is the phrase used to describe methods used by related service providers to put educationally related strategies into motion. Related services can use inclusionary practices within classroom settings, as advocated in the literature, or use practices that are outside the class environmental contexts. The manner in which service delivery practices are conducted is considered to be influential to educational outcomes, such as in IEP objectives and satisfaction of team members. Five service delivery practices (McWilliam, 1996) were examined in this study: Location of Services; Environmental Context; Presence of Other Children; Focus of Intervention and Role of Therapist.

The study focused on one related service, occupational therapy and the purpose was twofold. The first was to describe the type of service delivery practices used by occupational therapy in a large metropolitan school district. The second was to explore any relationships between these practices and IEP objectives met, and between these practices and teachers' perceptions of occupational therapy contributions to student skill development.

The results indicated that inclusionary service delivery practices were frequently used. Inclusionary service delivery practices showed moderately positive correlations to the teachers' perceptions that occupational therapy contributed to students' skill development. However, no correlation was noted between service delivery practices and IEP outcomes, perhaps due to the limitation in the IEP measurement procedures. The results indicated that the teachers were positive about the

occupational therapy contributions to student education. Teachers' perceptions of related service contributions may be considered valuable educational outcomes to be monitored by team members. The results provide preliminary data that inclusionary school environments, presence of peers, and functional focus of interventions are valuable for educational programs in which several professions contribute to the interventions.

The service delivery practices of related services are those educational services designed to assist students with disabilities obtain benefit from school programs. Service delivery practices involve the methods in which the related service intervention strategies are put into motion. The manner in which these practices are provided to students is an important factor in the success of educational intervention programs (Council for Exceptional Children, 1993; Giangreco, Edelman, Luiselle & MacFarland, 1996; Meyer & Eichinger, 1994). When a related service is included in a student's IEP, the educational team determines how, when, where and by whom this service will be provided because of its proposed impact on the student skill development and on the teachers, parents and peers supporting the student.

Service delivery practices may be thought of as occurring on a continuum from being isolated in nature to inclusionary in nature (McWilliam, 1996; Szabo, 2000). Isolated related service interventions have been described as those that are directly provided by a related service professional and away from the student's classroom, class activities and peers. Isolated interventions may involve less team collaboration between the teachers and related service personnel because there is less contact time between the teacher and related service personnel. Inclusionary related services are those in which the related service interventions are provided within the classroom setting, and incorporated within the educational context and with peers. Physical proximity of the related service personnel in the classroom allows for increased team collaboration with the teacher over isolated intervention. Inclusionary practices have been embraced as guiding principles by education and related service professions (American Occupational Therapy Association, 1999; Council for Exceptional Children, 1993; Meyer & Eichinger, 1994). Inclusionary related services are more closely aligned to the least restrictive environment provision of IDEA-97 than isolated related service practices.

Educational and related service literature enumerates various service delivery practices to be considered in the provision of related service inter-

ventions to students with disabilities (Giangreco, 1996; McWilliam & Bailey, 1994; Rainforth, York & Mcdonald, 1992). Five service delivery practices, as defined and described by McWilliam (1992), were the focus of this study: 1) selection of the location of services; 2) environmental context of the related service intervention; 3) presence of other students during the related service intervention; 4) intervention model or focus; and 5) role of the related service personnel in implementation of the intervention. These practices are briefly discussed below with an emphasis on one related service, occupational therapy.

LOCATION, CONTEXT AND PRESENCE OF PEERS

The location selected and the environmental contexts of service delivery have been important issues to special educators and related service professionals particularly since the passage of PL 94-142, as related services moved from a medical model to an educational model, incorporating the concept of least restrictive environment (Barnes, Schoenfeld & Pierson, 1997; Cole, Harris, Eland & Mills, 1989; McEwen & Sheldon, 1995). The federal regulations around least restrictive environment stipulate that students with disabilities be educated with nondisabled students to the maximum extent appropriate (IDEA, 1997). Giangreco (1996) emphasized that the determination of the least restrictive environment for a student should take into account location, ongoing educational activities and social acceptability of the related service intervention.

Related service interventions may occur in a separate setting away from the student's classroom, the on-going classroom activities with other students or within a classroom setting among peers, and within the environmental context of ongoing classroom routines. The former has been associated with an isolated intervention ("pull-out") model, while the later has been associated with an inclusionary model of related service intervention (Barnes, Schoenfeld & Pierson, 1997; Dunn, 2000). Several studies have shown that teachers and related service professionals preferred inclusive settings to isolated settings for the provision of related service interventions (Cole, Harris, Eland & Mills, 1989; Dunn, 1990; Inge & Snell, 1985). However, the effect of location, context and presence of other students on student skill development has been difficult to determine for related services, because only a few unrelated studies, targeting differing student skills, have addressed these issues. In two studies, one an experimental comparison design (Cole, Harris, Eland & Mills, 1989) and the other a small, time-series design (McWilliam, 1996), no difference was found in location of intervention for student skill

attainment. In contrast, in two time-series research studies of related service interventions, improvements in student skill development were noted in inclusive settings over isolated settings (Giangreco, 1986; Karnish, Bruder & Rainforth, 1995). Further investigation is needed to determine the impact of each service delivery practice (location, context and presence of peers) on the educational outcomes of related services.

FOCUS OF INTERVENTION

Focus of intervention involves the degree to which related service interventions target functional skills for a student verses targeting the development of prerequisite or remedial skills. In a functional focus of intervention, the purpose of intervention is to improve skills that are immediately useful for the student within the educational context, such as handwriting or playground games (McWilliam, 1996). In a developmental/prerequisite or remedial focus of intervention, the purpose of the intervention is to improve prerequisite skills that may eventually lead to acquisition of a functional skill, such as the development of trunk rotation or thumb opposition. Intervention that is focused on functional skills usually is considered to be of an inclusionary approach because the skills may be related to actual classroom contexts and behaviors. Inversely, remedial or developmental intervention has been associated with an isolated approach because the frequently used equipment (such as large balls or suspended swings) may be located outside the classroom setting and the targeted skills may not be immediately useful in the classroom. The focus of related service intervention has been a concern cited in educational and occupational therapy literature (Case-Smith, Rogers & Johnson, 2001; Hanft & Place, 1996), yet scarce coverage of this issue is found in the research literature (Kemmis & Dunn, 1996; McWilliam, 1992). In a study of occupational therapy interventions, Kemmis and Dunn (1996) explored the difference in student outcomes following the use of remedial and of functional interventions. The results indicated there were no differences in student outcomes between using the two approaches. However, the involved professionals preferred the functional to the developmental intervention approach. Further research is warranted concerning the focus of related service interventions within school systems.

ROLE OF THERAPIST

Designation of the trainer for related service intervention is a much-disputed service delivery issue. This concern centers on the designation of the

trainer(s) for those programs that may be considered within the expertise of a specific related service (Dunn, 2000; Giangreco, 1986). At issue is whether a related service professional will directly conduct a program with a student (direct intervention or "hands on") or will he or she collaboratively develop the program with the teacher so the teaching staff may conduct it (indirect intervention or consultation) (Rainforth, York & Mcdonald, 1993). Several considerations have been expressed in the literature (Dunn, 1988; Nesbit, 1993). Direct intervention provided solely by the related service professional may allow a student to benefit from a specific expertise of that professional. For example, an occupational therapist may conduct a 1 to 1 sensory awareness program with a student who has difficulty tolerating his or her sensory environment. Direct intervention has been associated with the concept of isolated intervention, that is, the related service personnel provide the intervention away from the teacher and classroom. On the other hand, when the teaching staff conducts the program in collaboration with the input of the related service professional, there may be increased training time and an increased chance for generalization (Rainforth, York & Mcdonald, 1992). For example, an occupational therapist and teacher collaboratively develop a classroom program in which a student with poor sensory tolerance can use a relaxation procedure with the teacher through out the day in order to stay on task. Interventions conducted by the teachers with the related service professionals are associated with an inclusionary approach. An option that is infrequently mentioned in the literature is that the team may decide that a combination of direct and consultative interventions may be the best approach for a student with a disability. For example, an occupational therapist may come into a classroom once a week to conduct a direct intervention and to make any intervention modifications and the teacher conducts a related program for the rest of the weekdays.

In recent years, special education and related service literature indicates that the collaborative intervention of the inclusionary model is preferred over the direct intervention of the isolated model for most students in public schools (American Occupational Therapy Association, 1999; Giangreco, 1996). Unfortunately, literature reviews have provided little data concerning the relationship of the designated trainer options to student skill attainment (McWilliam, 1994; Dunn, 1990). An understanding of trainer choice decisions and the relationship to student outcome is needed.

Literature indicates that the manner in which the above service delivery practices are provided is important for the intervention outcomes for students with disabilities. Unfortunately, the research concerning these service delivery practices has been inadequate. Little research has been conducted to

study the relationship of these practices to educational outcomes (Giangreco, Edelman, Luiselle, & MacFarland, 1996; Olsen, 1994; Rourk, 1996). Further research is needed to describe services delivery practices and to determine their relationship to educational outcomes. An understanding of any relationship of these practices to educational outcomes would provide a base for development of effective service delivery practices for related services.

This study focused on one related service, occupational therapy and the purpose was twofold. The first purpose of this study was to describe the type of occupational therapy service delivery practices in a large metropolitan school district. The second purpose was to explore any relationships between these service delivery practices and student individualized education program (IEP) objectives met, and between these practices and teacher perceptions of occupational therapy contributions to student skill development.

METHOD

Design

A descriptive, correlational research design was used in this study. Survey instrument and student records were used as the data sources. Outcome variables were 1) percentage of IEP objectives met and 2) teachers' perceptions of occupational therapy contributions to student skill development. Service delivery variables were the following five practices: 1) location of occupational therapy intervention; 2) environmental context of occupational therapy intervention; 3) presence of other children during occupational therapy intervention; 4) focus of occupational therapy-related intervention (directed toward prerequisite skills or directed toward functional skills); and 5) occupational therapist's role in intervention (direct intervention or consultative intervention) (McWilliam, 1992). These five variables were rated on Likert scales with responses that were considered to be isolated in nature rated 1, to responses that were considered to be more inclusionary rated 5.

Participants

The participants were 40 teachers of students who received occupational therapy services as indicated on the students' IEPs. Their names were obtained from the randomly selected files of students receiving occupational therapy in the school district. The mean number of years taught by the participants was 13 with a range of 1–28 years.

Data from IEP files of the students were compiled. The students were from different schools throughout the school district. Sixteen of the 20 school district's occupational therapists were the providers of occupational therapy services to the students. Table 1 shows student data.

Instrumentation and Procedures

A questionnaire, "Teacher Questionnaire about Occupational Therapy with Special Education Student" was developed for this study and contained four parts. Part I contained five items about the five service delivery practices of occupational therapy, which were adapted from a survey by McWilliam

TABLE 1
Student Information (n = 47)

Occupational Therapy Weekly Amount	
< 0.5 hour	10
0.5 hour	21
0.75 hour	1
1.0 hour	14
Special Education Classifications as Reported in IEPs	
Auditory, Hearing or Visual Impaired	6
Multiple Disabilities	3
Traumatic Brain Injury	2
Mental Retardation	4
Non-categorical	3
Learning Disabilities	5
Autism	6
Orthopedic Impairments	9
Other Health Impairments	14
Speech Impaired	36
Note: Some students had more than one classification. Mean number of classifications was 1.9.	
Age Range of Students	
2 years 9 months–7 years	24
7 years 1 months–11 years	15
11 years 1 months–15 years 3 months	8

(1992) entitled, "Providing Center-based Occupational Therapy Services in Early Intervention: A Survey." Each of the five service delivery practice items were ranked on a five-point Likert scale from responses that were considered to be of an isolated intervention approach (1), to responses that were considered to be of an inclusionary intervention approach (5). For example, the teachers were asked to score the service delivery practice item, "Presence of Other Children," by ranking their response on a scale from (1) "other children are never present during therapy," to (5) " other children are always present during therapy." Similarly, the "Role of Therapist" item was ranked on a scale from (1) OT's only role is to provide direct therapy for the student," to (5) OT's role is to consult with you."

Part II contained items about team collaboration practices, which is not reported in this paper. In Part III, teachers were instructed to respond to the statement, "Occupational therapy services have contributed to the skill development of this student in . . ." of the six skill areas (academic, social/behavioral, transitional, home, work/vocational and preacademic/prerequisite skills) by ranking their responses from strongly disagree (1) to strongly agree (5) on a five-point Likert scale. Part IV requested the number years taught by the participants. Lastly, a section was provided for comments about service delivery practices.

Procedures were conducted to ensure clarity and content validity of the questionnaire. Four university occupational therapy faculty members reviewed the questionnaire. All indicated the content areas were relevant and made minor modifications to the wording and format. Additionally, eight public school teachers who worked with occupational therapists and six public school occupational therapists provided input concerning the questionnaire items. Each was asked to rank the clarity and importance of each item using a scale of 1–5 (1 = strongly disagree, 5 = strongly agree). Their input was positive about the importance and clarity of the questionnaire with a mean score of 4.7 for importance and 4.5 for clarity.

In addition to the questionnaire, data were obtained from the students' IEP files: demographic information about the student, weekly amount of occupational therapy services, total IEP objectives, and whether the IEP objectives were met or unmet at the completion of the school year.

This study was conducted in a large metropolitan school district. The author directly distributed questionnaires to participants at their school. Each participant was allowed to privately and confidentially complete a questionnaire about the selected student receiving occupational therapy in his/her class.

RESULTS

Descriptive statistics are provided for the Service Delivery Practice variables: location of occupational therapy intervention; environmental context of occupational therapy intervention; presence of other children during occupational therapy intervention; focus of occupational therapy-related intervention; and occupational therapist's role in intervention. The correlation among the Service Delivery Practice variables and the two outcome variables, Percent IEP Objectives Met and Occupational Therapy Contribution to Skill Development are presented. Additionally, comments about service delivery practices are summarized.

Occupational Therapy Service Delivery Practice Variables

Table 2 provides the percentage of respondents who responded in each Likert category (1 = isolated response; 5 = inclusive response) for the five Service Delivery Practice variables. The Focus of Intervention variable had the highest inclusionary score of 82.5% of which the respondents indicated that most or all of therapy interventions involved skills that were immediately useful for students. The Location for Services variable had a score of 50% of which

TABLE 2
Respondents' Ratings of Occupational Therapy for Five Service Delivery Practices (n = 40)

	Percent of teachers who ranked each practice from isolated practice (1) to inclusive practice (5)				
Service Delivery Practices	1	2	3	4	5
1. Location for services (mean = 3.05, SD = 1.55)	25	17.5	7.5	27.5	22.5
2. Environmental context (mean = 2.88, SD = 1.52)	30	15	7.5	32.5	15
3. Presence of other children (mean = 2.85, SD = 1.53)	25	27.5	5	22.5	20
4. Focus of intervention (mean = 4.10, SD = 1.10)	7.5	0	10	40	42.5
5. Role of therapist (mean = 2.63, SD = 1.00)	5	50	32.5	2.5	10

the respondents indicated that most or all of the therapy activities were provided in the students' class settings. The percent scores for Environmental Context and Presence of Other Children were approximately split between most or all within the classroom context and with peers and some or all outside the classroom context and away from peers. Lastly, in contrast to the other service delivery variables, percent scores for Role of Therapist were 12.5% for most or all of the occupational therapist's role being consultation with the teacher and 55% for most or all direct therapy for the student.

Cronbach's alpha (coefficient alpha) was computed to determine if the Service Delivery Practice variables could be grouped to obtain one overall Service Delivery scale score to be used in the correlation with the student outcome variables. Cronbach's alpha is a statistic use as a "reliability index that estimates internal consistency or homogeneity of a measure composed of several items or subparts" (p 383) (Polit & Hungler, 1985). A coefficient alpha score of .861 was obtained (mean = 3.10, standard deviation = 1.09). This indicated that the relationship among the variables was strong enough to allow for a representative overall score for the service delivery practices.

Percent IEP Objective Met

Of the 40 surveys returned from the teachers, there were 33 corresponding IEP objectives that had year-end results reported. The mean number of IEP objectives was 28 with a range of 2 to 89. The mean percent IEP objectives met was 61% with a range from 0 to 100%.

Occupational Therapy Contributions to Skill Development

The 40 respondents' perceptions of occupational therapy contributions to the students' skill development were quantified on the questionnaire. Each was asked to rank a response for each skill area to the following statement: "Occupational therapy services have contributed to the skill development of this student in: (academic, social/behavioral, transitional, home, work/vocational and preacademic/prerequisite skills). The five variables were scored on a Likert Scale (1 = strongly disagree, 5 = strongly agree). Data indicate that the respondents agreed with the statement regarding occupational therapy contribution to skill development in all areas, with strongest contributions in academic and preacademic/prerequisite skills (Table 3).

Additionally, Cronbach's alpha (coefficient alpha) was conducted to determine if all student skill areas variables could be grouped as one overall scale score. A coefficient alpha score of 0.89 was obtained (mean = 3.41 and standard deviation = 0.86). This allows an overall scale score to be used in

TABLE 3
Respondents' Ratings of Occupational Therapy Contribution to Skill Development (n = 40)

	Percent respondents ranking agreement to the statement about OT contribution to skill development from strongly disagree (1) to strongly agree (5)				
Skill Areas	1	2	3	4	5
Academic skills	7.5	7.5	22.5	47.5	15
Social/Behavioral skills	10	12.5	30	40	7.5
Transitional skills	7.5	7.5	32.5	37.5	15
Home skills	10	5	45	30	10
Work/Vocational skills	7.5	2.5	37.5	42.5	10
Preacademic/Prerequisite skills	10	5	22.5	47.5	15

the correlations between the Service Delivery Practice variables and the Occupational Therapy Contributions to Skill Development variable.

Correlations Among Service Delivery Practice and Student Outcome Variables

Table 4 provides data of the Spearman rho correlations between the six service delivery variables with the two outcome variables (Percent IEP

TABLE 4
Relationship Between Service Delivery Practice and Student Outcome Variables

Variables	Percent Objectives Met (n = 33) (p > .05)	OT Contribution to Skill Development (n = 40)
Location for services	0.17	0.40 (p < .01)
Environmental context	0.07	0.36 (p < .05)
Presence of other children	0.04	0.48 (p < .01)
Focus of intervention	–0.20	0.34 (p < .05)
Role of Therapist	–0.09	0.23 (p > .05)
Service Delivery Scale Score	0.03	0.46 (p < .01)

Objectives Met and Occupational Therapy Contribution to Skill Development). Of the correlations between the service delivery variables and Percent IEP Objectives Met, there were none above .20 and none were statistically significant ($p > .05$). All of the six correlations between service delivery variables and Occupational Therapy Contribution to Skill Development were found to be positive. The Role of Therapist variable had a correlation of rho = 0.23 and was not significant ($p > .05$). The remaining five (Location for services, Environmental context, Presence of other children, Focus of intervention, Role of therapist and the Service delivery scale score) were significant ($p < .05$) and had correlations between rho = .34 and .48.

Respondents' Written Comments

Twenty comments were made about occupational therapy service delivery practices. Of these, 16 respondents made positive comments about the contributions of occupational therapy to student skill development and about service delivery practices. "Having the OT work in the classroom has been much more effective than removing student from class." "Excellent resource for inclusion process. He helped the student become successful with classroom activities." "This student has been in OT for several years. Handwriting, which was illegible through end of 3rd grade, became very legible early in 4th grade, so efforts by OT, Spe.Ed. teacher, and classroom teacher have paid off." Four comments provided suggestions about service delivery practices concerning scheduling difficulties and need for increased inclusionary practices. "I would very much like to see OT provided in the classroom as we (sp. ed. inclusion) provide our services in the classroom and have observed many benefits for all involved teachers, students (reg. & sp. ed.), parents."

DISCUSSION

The results of this study indicate that teachers and occupational therapists of this school district were using service delivery practices that were in keeping with inclusionary best practices for a large percent of the students in four of the five service delivery practices (Table 2). Particularly noteworthy was the high percentage of responses that indicated occupational therapy interventions were immediately useful for the students. This supports the literature's call to make related services relevant to the students' classroom tasks as opposed to interventions solely designed to develop prerequisite skills

(Karnish & Dunn, 1996; Meyer & Eichinger, 1994). When related service interventions target classroom tasks similar to those of the student's peers, a more inclusionary model is supported.

The results show that for approximately 50% of the occupational therapy services, the interventions were in the classrooms and incorporating the environmental context and peers. Thus, for this group the occupational therapist's input was inclusionary and relevant for the children's role as students. While approximately half of the group did not use inclusionary environmental contexts with peers, the study does indicate that the inclusionary model was in practice for this related service.

The service delivery variable, Role of Therapist, showed that occupational therapists were utilizing more direct intervention then consultative interventions. This indicated that the occupational therapists were working in a one on one manner with the students' interventions. This contrasts the "best practices" cited in the literature, which calls for more "consultative" or "supervisory" models (Giangreco, 1996; Rainforth, York & Mcdonald, 1992) and is in contrast to the more inclusionary results of the other four service delivery practices in this school district. This result may be due to the teachers' observations of direct occupational therapy intervention within the classroom and among peers. Occupational therapy interventions appeared to be "inclusionary" for location, environmental context and presence of peer; despite the fact that the therapists frequently conducted the interventions. It is possible that the characterization of "direct therapy" as an isolated practice may be out-dated, provided the occupational therapist works in concert with the teacher and within the classroom and the ongoing activities with peers. Who conducts an intervention program may not be as important as the actual student tasks and environmental contexts that the related service is impacting. The "role of therapist" within inclusionary settings is a service delivery practice area ready for future research.

The majority of the teachers felt occupational therapy intervention contributed to the student skill development areas of academic, social/behavioral, transitional, home, work/vocational & preacademic/prerequisite. Because student IEP outcomes may be difficult to objectify due to the individualized nature of IEPs, teacher perceptions may be considered an important educational indicator or outcome of the impact of related services. Educational outcomes measures other than IEP objectives, such as this measure, may be of value for schools to determine the benefit of related services. When interventions of related services are encompassed within the curriculum of students and all team members share the IEP objectives, it may be difficult to determine the related service contributions from that of the

contributions of the teachers. This is a positive inclusionary phenomenon because "seamless" programming may be provided for the students without obvious changes in classroom activities. However, this makes accountability and demonstration of contributions of related services more difficult. Thus, the use of additionally educational outcome measures of related services contributions, as perceived by other team members, may help educators; parents and administrators quantify and assess the educational endeavors and contributions of related services.

There were no significant relationships between the Service Delivery Practices and student IEP objective outcomes. This does not support the literature that indicates service delivery practices influence student educational outcomes. The lack of a significant relationship may have been influenced by the use of the dichotomous scores (met or not met) for the IEP objective outcomes, limiting the sensitivity of this dependent variable and contributing to the lack of significant relationship between the IEP objective outcomes and the Service Delivery Practice variables. This finding is in contrast the teachers' perceptions that occupational therapy services contribute to student skill development. The use of all IEP objectives (instead of targeting selected objectives) may be considered a limitation to the sensitivity of change, also. The relationship of IEP outcomes and service delivery practices should be further researched using more sensitive IEP measures and targeting specific school performance IEP objectives in which the related service contributed.

In contrast, the Occupational Therapy Contribution to Skill Development outcome showed a positive correlation ($rho = 0.46$, $p = .01$) with the overall Service Delivery scale score. This indicates that there was a moderate positive relationship between the degree of inclusionary practices and teacher perceptions of occupational therapy contributions. Thus as the occupational therapist used more inclusionary practices, the teachers felt the occupational therapist was contributing more to student skill development. The two highest correlations were Presence of Other Students and Location of Services with the Occupational Therapy Contribution to Skill Development outcome. This indicates that these inclusionary contextual factors may contribute to student skill development more than isolated intervention practices. These results cautiously support literature that stresses that inclusionary practices positively influence student outcomes (Giangreco, 1996; Karnish, Bruder & Rainforth, 1995).

The only service delivery practice that was not significantly correlated to Occupational Therapy Contributions to Skill Development was the Role of Therapist variable, indicating that the teachers' perceptions of occupational

therapy contribution was not influenced by whether the occupational therapist used direct therapy or indirect consultative procedures. Perhaps, teachers were more concerned about the actual input to the students' programs and how it fit into the classroom context than the role designation of those involved. Results of this study suggest that issue of "role designation" may not be as important as the location, context, and presence of peers and outcomes of interventions. As long as the related service professional can provide meaningful input to the IEP, the use of the term direct or consultative may not be important. Generalization of these results should be considered with caution as the results involved correlational data.

Educators, administrators, and researchers may view these results as indications that inclusionary practices were used in this school district and that teachers were positive about the occupational therapists' contributions to the students' education. The teachers' perceptions of related service contributions to student outcomes might be considered a valuable educational outcome to monitor when students receive related services, particularly within inclusionary contexts involving "shared" IEP objectives. While the results of this study should be viewed as preliminary due to the small sample and use of correlational data, the results indicate that inclusionary classroom environments, presence of peers and functional focus of interventions may potentially be considered influential factors of educational outcomes associated with related service interventions.

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EDUCATIONAL AND PSYCHOSOCIAL IMPLICATIONS AFFECTING CHILDHOOD CANCER SURVIVORS: WHAT EDUCATORS NEED TO KNOW

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ABSTRACT

The number of students who survive serious illness is increasing. As a result of recent medical advances that have increased both the life expectancy and the functional capacity of students diagnosed with childhood cancer, the return to school often shortly follows the initial hospitalization. This article discusses the physiological effects of this disease and its treatment and how it impacts the student educationally and psycho-socially. Also included are the medical statistics, legislative mandates for providing needed academic support, interventions that accommodate and modify the educational program to address individual needs, and strategies for preparing classmates for the returning student.

Although childhood cancer is relatively rare, an estimated 9,100 new cases are expected to occur in children from birth through age 14 in 2002 (American Cancer Society, 2002). Annually approximately one million individuals are diagnosed with cancer. When a child is determined to have cancer, the goal has always been to find a treatment that would result in a cure, a chance that the child would have the opportunity for a life beyond childhood. In recent years, the prognosis has been improving as the number of children who survive catastrophic illness, such as cancer, has been increasing with advances in medical treatment. The five-year survival rate for all childhood cancers is 77% (American Cancer Society, 2002). There has been a dramatically improved survival rate for children diagnosed with leukemia

(cancers of the blood-producing tissues), lymphomas (cancers of the lymphatic system), brain tumors, bone tumors and other malignancies. The site of the primary cancer is the determinant for specific types; Hodgkin's disease is 92% survival; Wilm's tumor (kidney) is 92%; acute lymphocytic leukemia (ALL) is 85%; osteosarcoma and Ewing's sarcoma (bone cancer) is 73%; neuroblastoma is 71%, brain and central nervous system is 69% (American Cancer Society, 2002). Current statistics from the National Institutes of Health (2002) are promising, indicating that over the last 30 years, survival into adulthood has increased from 30 to 80 percent. The diagnosis of cancer is no longer a death sentence. Increasingly, it is considered a life-threatening chronic disease rather than a terminal illness (Varni, Katz, Colegrove, & Dolgin, 1994).

Historically, since such a small proportion of children survived childhood cancer, concern was not on the ravishes or the aftermath of the treatment. A growing number of children and adolescents, ranging from 6% to 15%, with estimates of up to 30% in rural communities, are living with chronic medical conditions, such as cancer, asthma, and diabetes (Hoffman, Rice & Sung, 1996; Stein & Stiver, 1999). In the early 1970's, although there were not many long-term survivors, oncologists began studying the effects of childhood cancer treatment (Bain, 1995). There are increasing reports in the medical literature that the ramifications of treatments that increase the rate of survival frequently have serious effects on children's ability to cope with standard school requirements. Children who survive the ravages of cancer and conventional adjunctive therapies often experience a decline in mental functioning, intellectual quotient (IQ) and academic achievement (Thompson et al., 2001). This is evidenced by their difficulty acquiring and retaining new information, secondary to one or more cognitive processing deficits (Brouwers & Poplack, 1990; Lockwood, Bell, & Colegrove, 1999; Rodgers, Horrocks, & Britton, 1999). These cognitive side effects are generally manifested by delays in information processing, short and long term memory impairment, poor retention of new learning, disorganization, visual-spatial-motor planning dysfunction, attention and vigilance problems, slow mental processing; and disturbances in spatial orientation, sequencing, and problem solving abilities (Brown & Madan-Swain, 1993). Academic performance may be significantly influenced by the neurological effects of the disease and its treatment, such as a decline in performance between two and four years after initiation of treatment that resembles a nonverbal learning disability (Rubenstein, Varni, & Katz, 1990). This decline in academic functioning is hypothesized to be due, at least in part, to prolonged intrathecal chemotherapy, a prophylactic treatment modality, now used in place of cen-

tral nervous system radiation and recognized to cause cognitive impairment (Brown et al. 1996).

The two types of cancer that account for more than 50% of all pediatric cancers, acute lymphoblastic leukemia (ALL) and malignant brain tumors (BT), have direct impact on the central nervous system (CNS). The location of the tumor, the impact of chemotherapy and radiation used to treat these and other forms of childhood cancer frequently impair intellectual development. The most serious effects result from high-dose radiation to the brain used to treat specific forms of brain tumors. However, low-dose radiation and chemotherapy often produce less severe, more subtle and often later occurring learning disorders. The age of onset and subsequent treatment can also significantly impact the degree of neurological impairment suffered. Particularly vulnerable are the youngest victims, those three years and younger (Bain, 1995; Van Dongen-Melman, DeGroot, Van Dongen, Verhulst, & Hahlen, 1997). Researchers have reported significant losses in IQ for children over two years old with greater losses noted in children under seven years of age. With more than 40 percent of all childhood cancers occurring in the very young child, age four years and under (American Cancer Society, 2002), the damage to the developing brain and nervous system can have devastating effects. Long-term survivors of childhood cancer are at-risk for neuropsychological as well as cognitive deficits (Ris & Noll, 1994; Roman & Sperduto, 1995). Frequently these effects are of sufficient severity to impair future academic performance, employability, and quality of life (Armstrong, Blumberg, & Toledano, 1999; Haupt, Fears, & Robison, 1994; Mostow, Byrne, & Connelly, 1991).

Standard treatments, including surgery, chemotherapy and radiation that are used to save the life of the patient often produce other less desirable effects, such as damage to organs, impaired or altered growth, impaired fertility, limb amputation, and subsequent second cancers (Bains, 1995; National Cancer Institute, 2001). Additional immediate as well as long-term physiological side effects often include chronic pain, loss of energy, muscle weakness, loss of sensation/partial or full paralysis, fatigue, sleep problems, irritability, behavior changes, mental confusion, nausea/vomiting, diarrhea/constipation, anemia, visual impairments, muscle aches, and mouth sores. Addition repercussions include a compromised immune systems that often will result in increased risk of contracting common infectious diseases that could have very serious medical implication for the child with cancer (National Cancer Institute, 2001). Significant effects specific to the introduction of chemotherapeutic agents have potential long-term impact on the learning process; cisplatin-induced hearing loss, adriamycin-induced heart

muscle damage, and methotrexate-induced brain damage (Thompson et al., 2001). The aesthetic side effects that often are most traumatic to students' psychosocial adjustment include loss of scalp head, eyebrow and eyelash hair, surgical scars, weight loss or gain, and damage to enamel on teeth resulting in discoloration (National Cancer Institute, 2001).

THE ISSUE OF SCHOOL REINTEGRATION

With advances in biomedical science, pediatric oncology, and medical technology, many treatments can be administered and monitored on an outpatient basis; thus, more children are returning to school after initial hospitalization. Parents of children with chronic or catastrophic illness comment on the value of reintegration into school as a normalization process, as a means for children to begin to regain control over their lives. School attendance serves as an aid to recovery, and as a context in which children can succeed, experience friendship and be distracted from their medical problems (Bessell, 2001; Bolton, 1997; Closs & Burnett, 1995).

In order to facilitate a smooth and successful transition to school, it is critical that the educational community understands and appreciates the impact that catastrophic illness has on children and their school life. In order to make appropriate educational decisions, determine necessary accommodations, and provide needed services and supports for children's reentry into the classroom, teachers need to have an awareness and understanding of, not only children's medical condition, but how their educational, physical and social-emotional needs should be addressed.

THE LEGAL AND EDUCATIONAL RIGHTS OF THE CHILD WITH CANCER

An estimated 40% of children and adolescents with chronic health problems experience school-related problems (Thies & McAllister, 2001). Even when serious illness and/or its treatment do not directly impact children's cognitive development, it can affect the child's academic functioning and emotional adjustment in numerous ways (Lightfoot, Wright, & Sloper, 1999). These students often have unmet learning needs resulting from chronic absenteeism, disease symptoms or side effects of medical interventions (Thies & McAllister, 2001).

Although there are mixed research findings reported in the literature regarding the psychosocial affects of cancer and its treatment on school-aged

children, there are a number of studies that youth with chronic health conditions are at greater risk than their peers of developing academic and school related problems (Howe, Feinstein, Reiss, Molock, & Berger, 1993; Wallander & Varni, 1998). Factors that impact on school performance include absence from school and the emotional and social implications of the isolation that these children experience due to their limited school curricular and extra-curricular involvement (Fowler, Johnson, & Atkinson, 1985; National Institutes of Health, 2002; Nettles, 1994). Besides the academic and social adjustment problems these children experience, school retention and placement issues arise. Research findings on retention indicate that 26% to 47% of childhood cancer survivors are retained in a grade (Moore, Glasser, & Ablin, 1988; Mulhern, Wasserman, Friedman, & Fairclough, 1989). Results of a placement study by Madan-Swain et al. (1998), indicated that more than one-third of these students received part-time special education services and 7% were subsequently placed in full-time special education programs, while only 8% of the study participants met the minimal criteria for classification of learning disabilities.

These students are guaranteed an appropriate education through federal legislation (i.e., The Individuals with Disabilities Education Act, 1997). Children who have cancer are eligible for the classification of Other Health Impaired due to their "limited strength, vitality, or alertness due to chronic or acute health problems (Public Law 105-17, 1997). These children may also qualify for protection against discrimination under Section 504 of the Rehabilitation Act of 1973, as their medical condition "substantially limits him or her in major life activities," such as the learning process (Public Law 93-112, 1973).

THE COGNITIVE IMPACT OF CANCER ON THE LEARNING PROCESS

The areas of learning dysfunction generally resulting from the cancer process, chemotherapy and/or radiation treatment are characteristic of those processing problems noted in students with nonverbal learning disabilities. Advances in therapeutic intervention have changed the outcome for childhood survivors of cancer. During the 1970's to the mid-1980's, the treatment standard for patients with ALL was whole-brain or spinal radiation that often resulted in cognitive impairment and physical effects. Since the late 1980's, the medical community has recognized the profound impact that radiation has on the developing brain and therefore, current protocols rely more on high-dose chemotherapy than radiation therapy (National Cancer Institute,

2001). The effects of chemotherapy on children with brain tumors and ALL are often the inability to sustain attention and persistence for an extended period of time. Short-term memory deficits are evident in the classroom primarily in math, spelling and retention of facts, whereas, reading and remembering concepts and ideas tend to be less affected (Bain, 1995; Mirsky, Fantie, & Tacmao, 1995; Sohlberg, & Mateer, 1989). Academic difficulty, inconsistent performance, gaps in skill development, and inability to keep up with curriculum requirements often result from absences due to hospitalizations, medical treatments and tests, fatigue, and lack of stamina (National Cancer Institute, 2001). These academic problems need to be accurately diagnosed so an Individual Education Plan (IEP) can be developed and instructional programs can be modified to meet specific needs. It is important to note that some of the neurological and processing effects of radiation and chemotherapy may be more subtle or not evident until later years when academic demands change. During these later years, when the child appears to be in good health and their cancer history no longer seems to be relevant, teachers may not be aware of the residual effects that may impact the learning process.

THE EMOTIONAL-SOCIAL REPERCUSSIONS OF CANCER

Effects of cancer on the child are many. Not only does the diagnosis of cancer take a physical toll on those affected, it places them at increased risk for psychosocial adjustment problems. Although some researchers have found that children with cancer demonstrate only mild to moderate differences in adjustment among long term survivors (Gray et al., 1992; Kazak, 1994; Noll, Bukowski, Davies, Koontz, & Kalkarni, 1993), the findings of other researchers indicated that there is an increased risk for psychosocial problems (Greenberg, Kazak & Meadows, 1989; Varni et al., 1994). A recent study by Bessell (2001), indicated that while many children and adolescent cancer survivors report psychosocial adjustment patterns similar to the general population, scores on standardized instruments revealed that 42% of the study participants indicated general psychological distress including social anxiety, poor peer acceptance, and self-perception issues (p. 355). Feelings of being isolated can result from school absences and limitation on typical childhood activities (Bolton, 1997) and psychosocial adjustment can be compounded by poor academic progress (Lightfoot et al., 1999). Factors that seem to influence the impact that cancer can have include the age when the child is diagnosed, the type and severity of the cancer, the intensity of the treatment and the time since diagnosis (Varni, Blout, & Quiggins, 1998). It is clear that this

disease can have an impact on children and their family psychologically, spiritually and socially (Sloper, Larcombe, & Charlton, 1994; Wallander & Varni, 1998). According to the American Psychiatric Association's *Diagnostic and Statistical Manual (DSM-IV)*, one of the qualifying events for diagnosing posttraumatic stress disorder is "learning that one/one's child has a life threatening disease" (American Psychiatric Association, 1994, p. 424). Many who recover from the physical effects of this disease and its treatment (e.g., hair loss, changes in weight, fatigue, nausea) are at increased risk of psychosocial adjustment problems, including depression, chronic anxiety, fear of relapse, insecurity, embarrassment, frustration, guilt, feelings of being overwhelmed, and less ambitious ideals, (Varni et al., 1994; Wallander & Varni, 1998). Emotional energy usually spent mastering basic developmental skills is now used to cope with the illness (National Institute of Health, 2002). This disease robs the child of the invincibility of youth, forces them to face the harsh realities of painful and frightening treatments, and leaves them vulnerable to the possibility of the ongoing ravishes of this disease.

An additional repercussion of cancer is the impact on the amount of time available for normal activities of childhood. A large portion of the child's life continues to be dedicated to medical issues for years after the initial diagnosis. Social interaction with peers, a critical component of a normal childhood, particularly during adolescence, is often strictly limited at times when medical intervention is necessary or when vulnerability to infection is possible (Fowler et al., 1985; Nettles, 1994). This limited contact with peers, complicated by the physical changes of cancer, often leads to school reintegration problems, school phobia, social isolation, teasing, rejection and avoidance. This can create a reluctance to resume friendships and return to school, lowered self-concept, and a tendency to become withdrawn, to regress, or become belligerent (Lightfoot et al.,1999).

THE IMPLICATION OF AGE ON THE CANCER DIAGNOSIS AND ITS CONSEQUENCES

Age is a critical factor related to the physiological functioning, psychological coping processes, cognitive conceptions of cancer, as well as the compliance to treatment and outcomes (Kato & Mann, 1996). Young children's understanding of their critical medical condition and the interventions needed and their ability to articulate fears and questions is limited. Hand puppets or role-playing can be used to help children ask questions and to provide information in a non-threatening manner (National Cancer Institute, 2002). However, diagnosis and treatment during the adolescent years can cause

serous emotional and social distress. Cancer comes as an abrupt intrusion in a young adult's life (Goldstein, 1995). Unlike other normative and natural crises that occur in the developmental process, cancer is a sudden and shocking event for the middle and secondary school aged student (Goldstein, 1995). The adolescent years are a unique and stressful developmental stage in the life cycle without the complication of dealing with a catastrophic illness. At a time in life when teenagers are yearning to become independent, this disease forces them to be dependent on parents and caregivers. The normal activities of adolescence are limited due to medical treatments and often by overprotective parents, worried about the life threatening implication of this illness, who tend to tighten their grip and limit typical teenage freedoms that may lead to conflict (National Institute of Health, 2002).

THE PREPARATION OF TEACHERS AND CLASSMATES

It is important to ease the transition back into the classroom. Children with cancer may find the resumption of their school routine to be a major step toward regaining some control and normalcy in their lives. Teachers should have knowledge of the physiological, psychosocial and cognitive status and ongoing needs of these students. Parent-teacher collaboration is critical to reintegration success. Parents are usually open, willing and able to share information about their child; however, it is important for school personnel to keep in mind that parents are dealing with a great deal of stress and hardship. Parental input is critical in regulating an academic program that is sufficiently challenging yet not excessively rigorous for the already overburdened child. Parents can also be critical in maintaining a healthy balance between the academic and social needs of the child.

Close communication with families is required to determine what information can be shared about the particulars of the medical condition, what they have been through and what lies ahead. In addition, school personnel should be informed of the limits to what children want peers to know due to sensitivity or embarrassment and may be timid and very reluctant to discuss their experience. Other children find it cathartic and are eager to show their "battle scars".

Return to the classroom following the trauma of diagnosis and treatment of a life threatening disease can be anxiety provoking for both the young child and the adolescent. Hospitalizations, painful and exhausting treatments and the stress and anxiety caused by these traumatic experiences take a tremendous toll on the children, their siblings and parents. Additionally, when children do not reenter school early in their illness, if even for a short

period, they often find it much more difficult to return at a later time (Brown & Madan-Swain, 1993; Katz, Dolgin, & Varni, 1990). One of the major obstacles to a smooth re-entry to school is a tendency toward school phobia. This results from children's reluctance to return to school following a long absence complicated by the parent's tendency toward over protectiveness. The social transition can be particularly difficult when there has been little to no peer interaction since the diagnosis. Their school performance may be significantly impacted by the traumatic emotional and affective response to the life altering adjustments they make to survive cancer (Brown & Madan-Swain, 1993).

School modifications may need to include adjusted schedules, such as a shortened day, to meet the physical needs of students who may require medical attention, or fatigue easily and require rest breaks. Classroom locations may have to be changed for students who have limited physical capacity; they may require emergency intervention, those on crutches or in wheelchairs may need to be near an elevator or the nurse, or be placed in a room with good ventilation. After school tutoring and bedside instruction, at home or in the hospital, must be available for times when the student is unable to attend school due to treatment schedules or risk of infection. It is important to provide opportunities for these children to participate in appropriate extra-curricular activities; however, alternative roles may need to be assigned (e.g., the previous hockey player may maintain involvement as a score keeper).

School policies may need to be adjusted to accommodate the physical and/or psychosocial needs of the student (e.g., the attendance policy, the 'no headwear allowed policy'). Grade level curriculum standards, program requirements and state mandates may need to be modified in the IEP (e.g., substitute their physical therapy or an alternative requirement such as a research paper on a cardiovascular exercise for the standard physical education graduation requirement).

Classroom accommodations may include allowing more time to process and produce written and oral responses, workloads and assignments may need to be broken-down, modified and adjusted. Schedules should be as flexible as possible with important class activities planned around the time the child will be absent due to medical appointments and hospitalizations. These students need to be given opportunities to be involved in the planning process and to be allowed to make choices, to take some control over their learning experience since they often feel out of control in all other aspects of their lives.

The IEP should also include needed related services, such as counseling, speech-language, occupation and/or physical therapies, special transportation (e.g., wheelchair lifts), nursing services, note takers, interpreters. Technological supports should also be considered, including laptop computer access, video or audio equipment to facilitate communication, and devices to facilitate fine or gross motor skills.

THE IMPORTANCE OF PREPARING FOR THE REINTEGRATION

School personnel should acknowledge their personal biases and emotional reactions toward serious illness. They also need to recognize that diversity issues, such as the family's cultural perspective in dealing with illness, will likely impact the reentry process, and they need to understand how previously diagnosed disabilities may become more complex. Teachers need to realize the impact these factors have on their own ability to support not only the student with cancer but how they affect the other children in the class.

Peers can also be significantly affected by a classmate's illness. Many may never have been around someone who has been so seriously sick. Others may be frightened by the term cancer and have misperceptions about this illness and their personal risk being near the child with cancer. They may not be able to voice their concerns. Some may worry that cancer is contagious, that they can "catch" it, that it is spread through germs and thus, may be afraid to sit near or interact with the returning child. Some may be upset by the different appearance of their friend, and others may harbor the impression that death is inevitable because their grandfather died from cancer. Although classmates may have communicated with the child who was sick via phone calls, card or email, they may not have even seen the child and need to be prepared for the physical changes in appearance. They need to know that their classmate is the same person, just that they may be more susceptible to infection or injury and that they may need to play more carefully with their friend. When classmates have the opportunity to welcome one of their peers back into the inclusive environment of the classroom, it helps to promote understanding, empathy and camaraderie.

School personnel need to recognize the anxiety and uncertainty that children experience when a peer suddenly develops a life-threatening illness. They should listen to students' concerns, be patient and responsive to questions, and confer with specialists for information beyond their expertise. Often the parents or medical support staff are willing to talk to the class. An effective strategy is to have classmates discuss how they feel physically and

emotionally when they are sick, which can promote a feeling of empathy by having them think about how they would want to be talked to and treated under similar circumstances. It is important to explain the side effects of treatment so physical changes in the returning child's appearance will not come as a surprise. This should alleviate teasing as peers become sensitive, defend their classmate and help to fend off others who may be insensitive or offensive. Providing stories, case studies, and opportunities for role-playing will allow classmates to practice how they will be supportive and provide a means of coping most effectively with the situation. Presenting a lesson on cancer, its causes, types, treatment, and the side effects of treatment and assigning students to research related topics can help dispel myths and provide students with current information.

It is important, not only for the children with cancer but also for his peers, to maintain ongoing supportive communication. Close collaboration with parents is critical to determine the type and degree of interaction appropriate to meet the child's changing medical status. At times, visits or phone calls may be welcomed and encouraged, but, at other times, when the child may be too ill to interact, emails, cards or pictures are better forms of communication. Regular teacher-parent communication is important to keep the type of interaction meeting the child's changing needs.

Serious caution must be taken with peers who are not feeling well, coming down with the flu or colds and especially those who have been in direct contact with someone who has chicken pox, measles, or shingles. Exposure can cause very serious complications for the child with cancer. Therefore, actual or suspected exposures must be reported immediately to the parents or the school nurse.

THE ALTERNATIVE INSTRUCTIONAL PROGRAM

Federal and state legislation clearly dictates that the most appropriate setting for education is the school, considered to be the least restrictive environment, however, due to the need for hospitalization or home medical intervention, homebound instruction may be necessary (American Academy of Pediatrics, 2000). As a means of maintaining students' academic skills while they are hospitalized, in treatment centers or have nursing care in the home, an instructor is sent to the child to work individually, or in a small group while in a medical setting where other school-aged patients are receiving treatment (Public Law 105-17, 1997; Public Law 93-112, 1973). While the medical facility may provide a certified teacher to instruct these students, the home district is generally responsible for paying for this service, providing

textbooks and materials and an instructional plan. To ensure that students continue to be a part of the class even when they are absent due to hospitalization or treatment, modified assignments can be sent by means of email, fax, telephone, audio-video or written message to keep the child up-to-date with classroom happenings.

The type, length, and intensity of homebound instruction will depend on the medical status of the student. The instructional period is limited to, at most, an hour or two each day and will need to be adjusted according to the stamina of the child and the treatment schedule. Some students may be reluctant to do school work when they are trying to cope with their personal emotional turmoil, and feelings of helplessness or hopelessness. Although, according to Bessell (2001), there is a dearth of research evaluating the effectiveness of homebound or hospital-based instruction, often getting back into the routine of academics and getting their minds off their illness and into the normal business of school can be an important mental diversion, provide some routine and normalcy to their lives and help them to envision a future and life after cancer.

The homebound instructional program is often modified considerably when the child is dealing with the residual effects of chemo and radiation therapies. The lesson those days may consist of the teacher reading a story to the child who can only passively participate while on days when the child is feeling stronger, several subjects may be covered and assignment may be left for the child to complete later in the day. Often when instruction is individualized, more material can be covered so that the child can ultimately return to class without the added pressure of having to catch up. The goal is to provide a more seamless reentry into school and the class curriculum.

The instructor who comes to the child's home is generally not the same individual who provides instruction in the hospital or treatment center. The home instructor is generally sent from the school district and this individual takes over when the child returns home. As the student's physical stamina increases and during periods of the treatment when the risk for becoming contaminated (picking up germs) is not high, a modified school day may be arranged. Teachers need to be aware that attendance may continue to be an issue due to medical appointments and absences required to avoid exposure to influenza, and infectious childhood diseases such as chicken pox, in the classroom or even in other classes in the school, since these common diseases can have very serious implications for cancer patients. Curriculum requirements and even state mandates can be modified, if exceptions are clearly noted in the students' Individual Education Plan (IEP).

SUMMARY

The number of children who are diagnosed with catastrophic diseases, such as cancer, is on the rise. From the moment of diagnosis, the lives of these children are irrevocably changed (Bessell, 2001). The good news is that an increasing percent are long-term survivors and are able to return to school. Teachers need to become knowledgeable and sensitized regarding their students' medical conditions as well as their academic, physical, emotional and social adjustment and work-study skills. Teachers need to recognize the legislative rights of these children, placement and program options and sources of support in order to provide appropriate services. They need to become knowledgeable about the type of accommodations and teaching strategies needed to enable these students to deal with academic requirements, and to analyze the technological supports and related services that may be required.

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A CASE STUDY OF THREE PROFESSIONALS WITH CEREBRAL PALSY: FACTORS IN COMMON

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ABSTRACT

Structured interviews were conducted with three professionals with cerebral palsy to determine common factors among the group. Common factors found among the subjects were the following: educated in general education settings prior to legal mandates, obtained advanced college degrees, displayed average to high self-concepts, utilized a variety of adaptive devices in a creative manner, communicated openly about their disability, maintained stable marriages, and considered their disability in planning for the future. As a group, subjects also reported health issues attributed to their disability, resulting in secondary aging factors. Implications for future research are suggested.

Cerebral palsy is a non-progressive disorder affecting movement and posture. The condition can be caused by neurological damage during the prenatal, perinatal, or postnatal period. The four major categories of cerebral palsy include: spasticity, resulting from damage to the pyramidal system of the brain; athetosis, resulting from damage to the basal ganglia of the brain; ataxia, resulting from damage to the cerebellum of the brain; and mixed, the combination of two or more types (Gargiulo, 2003). The region of the body involved is typically divided into hemiplegia when only one side of the body is involved, diplegia when there is more involvement in the lower limbs versus the upper limbs, and quadriplegia when all limbs are affected equally

(Kirk, Gallagher, & Anastasiow, 2003). The degree to which an individual is affected is classified as follows:

Class I — No limitation of activity;
Class II — Slight to moderate limitation of activity;
Class III — Moderate to great limitation of activity; and
Class IV — Inability to carry out any useful physical activity without the support of assistive technology (Heller, Alberto, Forney, & Schwartzman, 1996).

The professional literature on individuals with cerebral palsy primarily investigates issues related to school age children. There appears to be a significant paucity in the current literature examining issues faced by adults with cerebral palsy, especially adults in professional settings. Therefore, the purpose of this study was to identify common factors among three professionals with cerebral palsy through a case study approach.

Although the literature on professionals with cerebral palsy is quite limited, researchers have investigated a restricted number of adult issues especially those concerning employment and independent living. Using a structured questionnaire with 130 young adults with cerebral palsy Van der Dussen, Nieuwstraten, Roebroeck, and Stam (2001) found that many adults are independent in activities of daily living, mobility, and communication, but tend to be less successful in employment. A questionnaire concerning demographic facts of 221 adults with cerebral palsy found that 24% of individuals worked full-time and 84% lived in their own home or apartment with or without supportive services (Andersson & Mattsson, 2001). Murphy, Molnar, and Lankasky (2000) reported that 84% of individuals stated they were overprotected as children; 80% wished that their physician was more knowledgeable about the condition of cerebral palsy; and 67% lived independently. In a descriptive study of 99 young adults utilizing a multiple regression equation it was found that the ability to obtain a job was highly dependent on receiving an education in a general education setting (Tobimatsu & Nakamura, 2000).

Magill-Evans and Restall (1991) utilized a seven year longitudinal study to examine the self-esteem of persons with cerebral palsy. As adolescents, females scored lower on physical, social, and personal self-esteem. Males scored similar to a control group. However, as adults these female subjects were no different from the control group. In a predictive study to determine future life outcomes, researchers determined that adults with cerebral palsy who were competitively employed tended to have milder involvement, higher IQs, and were educated in integrated schools (O'Grady, Nishimura, Kohn, & Bruvold, 1985). Sillanpaeae, Piekkala, and Pisirici (1982) followed young

adults for up to 25 years and found that adults with spasticity were employed at significantly higher rates compared to persons with athetosis or ataxia. Other significant factors affecting successful employment with young adults were mobility, manual dexterity, level of intelligence, and socialization skills. In an early study of 193 persons with cerebral palsy who attended college, the researcher determined that 90% of individuals were employed. However the rate of pay for these individuals tended to be less than their co-workers (Hutchinson, 1968). A recent fact sheet on aging and cerebral palsy reported that for individuals in their thirties and forties, an increase in joint problems, tight muscles, back and neck pain, gastro-intestinal problems, osteoarthritis, and an overall increase in pain and discomfort were common secondary aging effects (Scope, 2001).

The above results indicate that adults with cerebral palsy face many challenges and obstacles. However, a number of these individuals have experienced professional and personal success. A case study of professional adults with cerebral palsy would add to the understanding of the various factors that contribute to their success.

METHOD

This study was conducted using survey research methods, relying particularly on interviews consisting of a structured format in which open-ended questions were used. Three professionals with mild to severe cerebral palsy were contacted in person to request participation. These subjects were chosen as they were individuals with whom the researchers had ongoing professional interaction and were amenable to participation in this study. Following their agreement a mutually convenient time was established for an interview.

SUBJECTS

Subject 1—The first participant is a 49 year old male with severe spasticity/athetosis and has quadriplegia. His functional classification is between Class III and Class IV. This individual is the oldest of three siblings and has been married for ten years. He and his wife have one son who is in elementary school. This individual has a Ph.D. and currently works as a coordinator of disability services for a public university. He utilizes a power wheelchair for mobility and has a custom-designed adaptive cart into which he can roll his wheelchair for the one mile commute to work. He and his wife live

in a new home which was specifically designed to accommodate his physical needs.

Subject 2—The second participant is a 52 year old female with moderate spasticity/ataxia and has quadriplegia. Her functional classification is Class II. This individual is the second of four siblings and has been married for 30 years. She and her husband have one son who is in college. This individual has a master's degree and works as a special education teacher for a mid-size school district. She and her husband have a relatively new accessible home which fully meets her needs, but was primarily designed to accommodate her husband's business meetings.

Subject 3—The third participant is a 57 year old male with mild athetosis/spasticity. His functional classification is Class II. This individual is the oldest of four siblings and has been married for 26 years. He and his wife have a son and a daughter who have completed college and a daughter currently enrolled in college. This individual has a Ph.D. and works as a professor of curriculum and instruction for a public university. He and his wife have a large, two-story home which fully meets his needs.

INSTRUMENT

A set of 47 interview questions (see Appendix A) was developed to guide the interview process. A large group of questions was initially developed by the researchers and then extensively discussed with an individual who has cerebral palsy. Following this discussion, the questions were grouped under seven headings and reworded to establish some degree of consistency. The revised document was shared, again, with the same individual and approved. Validity and reliability were enhanced through a pre-interview discussion with one of the participants. As a result of this discussion, a question about birth order was added along with a question about parental discussions. Questions 21 and 37 were reworded to improve clarity.

The interview protocol consisted of seven sections: demographics, education, lifestyle, employment, marriage and family, medical, and future considerations. The shortest section was future considerations with three questions, while the longest section was employment with 11 questions.

PROCEDURE

To insure consistency across interviews, both researchers were present at each interview and an audiotape was made of each interview as well. Two of

the interviews were conducted in the individuals' homes while the third interview was conducted in the professional's office. The interviews lasted from 48–60 minutes. Following the completion of the interviews, the audiotapes were transcribed by one researcher and verified by the other researcher.

RESULTS

The following results were drawn from the structured interviews of the three professionals with cerebral palsy. Findings were identified and reported only when consensus was found among all subjects.

- All subjects were primarily educated in an inclusive environment which reflected both their parents' high expectations for them and their strong academic skills as evidenced by their advanced degrees. They were also fully involved in extracurricular activities. In addition, subjects reported that their parents took strong ongoing advocacy positions concerning their education. This advocacy occurred prior to the implementation of IDEA, Section 504, or ADA.
- Academic adaptations were often arranged by the subjects themselves, rather than through a formalized support system. Examples of academic adaptions that were useful to the subjects were oral testing, using a tape recorder to take notes, and using a typewriter for longer written assignments. One adaptation that was emphasized repeatedly by the subjects was the importance of informal peer assistance. The development and utilization of an informal network of student support enabled the subjects to succeed in the general education classroom without direct teacher interventions or major modifications.
- All subjects reported that simple, practical adaptions were especially useful in their lives. The adaptations mentioned by the subjects were commonly available rather than commercially designed for a person with physical challenges. Examples of various life-skill adaptations that were used by the subjects include: a straw for drinking, an electric toothbrush, a travel mug with a top, a cutting board with suction cups and prongs to hold and cut items, cooking a small meal in a much larger container, and increasing the viscosity of a liquid by adding ice to a drink.
- Subjects stated that specific discussions with their parents on the nature and various aspects of cerebral palsy were, at best, limited. However, they have discussed this issue freely and openly with their own children.
- Subjects, after a period of reflection, rated themselves as possessing average to high self concepts.

- Subjects reported that a stable marriage and supportive spouse enhanced both their professional and social lives. They further reported depending on their spouse for selected fine motor activities.
- Subjects reported handwriting was an obstacle in their everyday life, but most evident in practicing their profession. As a result subjects reported the need for an accessible work environment which incorporated the use of adaptations such as an engraved signature on a self-inking stamp, a scanned signature stored on the hard drive for computer generated letters, an electric self-correcting typewriter for short notes and telephone messages, and a modified keyboard and mouse.
- Salaries were reported to be middle income, ranging from $35,000–$65,000 per year. Also, it was reported that subjects factored the long-term effects of their physical disability into their financial planning.
- The subjects reported associated health problems related to their disability. They felt the added stress and strain on their muscoskeletal system resulted in exacerbated effects of aging. All subjects were on various medications to reduce muscle tension and were well satisfied with their family physician.

DISCUSSION

The purpose of this study was to identify common factors among three professionals with cerebral palsy. To accomplish this, the investigators conducted a structured interview with each professional. Based on the results of this study several findings are worthy of discussion.

All subjects attended a regular school and were fully integrated into the general education setting presumably leading to successful employment. Although this finding agrees with both Tobimatsu and Nakamura (2000) and O'Grady et al. (1985) it must be tempered by the fact that all three subjects were intellectually well suited to meet the academic rigors of a general education. While a general education setting was the most appropriate placement for these subjects, not all students with cerebral palsy will be able to meet this standard.

It is of interest that this phenomenon occurred prior to the general acceptance of the concept of inclusion. The parents of these subjects, while not professionally trained in pedagogy, were intuitively drawn toward an inclusive setting for their children with cerebral palsy. The teachers and administrators supported the parents' decisions based on the students' potential rather than legal mandates.

Self-concepts for the subjects were reported to be average to high. This appears to be similar to results found by Magill-Evans and Restall (1991). This finding is not surprising as all three subjects were employed in professional settings and reported long-term, stable marriages. Both factors, fulfilling employment and home life, undoubtedly affect self-concept positively.

All subjects attended college and held advanced degrees with salaries falling in the middle income range. This differs somewhat from early work by Hutchinson (1968) who found that college educated individuals with cerebral palsy were paid less than their nondisabled coworkers. The present finding may be tempered by the fact that all three subjects in this study were employed in educational settings with remuneration based on a state salary schedule.

In exploring aging, subjects reported increased health problems, such as strained tendons, torn tendons, neck and back pain, gastrointestinal problems, and reduced energy levels. They attributed this increase to a compounding effect of the normal aging process coupled with their cerebral palsy. Although cerebral palsy is generally defined as a nonprogressive condition, apparently the normal effects of aging are exacerbated by the disability. The health issues reported by these three subjects is not dissimilar from the information reported by Scope (2001). However, while the subjects in the Murphy et al. (2000) study reported dissatisfaction with the knowledge base of their physician, the subjects in the present study were well satisfied with the care and knowledge of their family physician.

An interesting finding to the investigators was the subjects reporting limited discussions with their parents about the various aspects of their disability. In contrast, the subjects had regular and open discussions with their own children. Hopefully, this reflects a generational trend where the subject of cerebral palsy and other motor conditions is now a much more approachable topic for family discussions. Further, this open communication may be an indicator of a reduction in the stigma previously associated with physical differences.

The investigators speculate that the subjects' creativity and skilled problem-solving may well have played a significant role in enhancing personal, academic, and professional success. The subjects utilized informal, self-developed sources of support rather than depending on legal mandates and formalized supports. This was evidenced by their statements concerning personal accommodations, adaptations, and the ability to network for support.

LIMITATIONS

Three limitations were noted by the investigators. These included a relatively small number of subjects, as is typical for a case study and potential occupational bias as all three subjects were employed in the field of education. Additionally, some items (i.e. 14 and 34) may have elicited gender based responses.

IMPLICATIONS FOR FUTURE RESEARCH

This investigation provides insight into common factors among three professionals with cerebral palsy. Because all subjects were professionals in the field of education, this study should be replicated with professionals outside this field. This appears to be one of the few investigations which examined health issues and secondary aging factors among individuals with cerebral palsy. This was an issue of significant concern for all three subjects and should be investigated in more detail. The subjects in this study were educated prior to the passage of major special education legislation. The study should be replicated with younger professionals with cerebral palsy who were educated after the passage of the Individuals with Disabilities Education Act and the Americans with Disabilities Act.

CONCLUSION

The investigators found that professionals with cerebral palsy exhibited the following common factors: educated in regular schools, obtained advanced college degrees, maintained stable marriages, displayed average to high self-concepts, communicated openly about their disability, utilized a variety of adaptive devices in a creative manner, and considered their disability in planning for their future. As a group, all subjects reported health issues they attributed to their disability. This case study revealed the common factors found among professionals with cerebral palsy. The study also illustrated how these professionals faced problems, developed adaptations, and sought solutions to the challenges of life.

APPENDIX A

Basic Description

1. Gender?
2. What was your age of diagnosis? Was the diagnosis definitive?
3. What was your birth order?
4. What is your current age?

Education

5. What type of educational placement did you attend K–12?
6. Did you participate in extracurricular activities such as sports, clubs, or band?
7. Did your parents have to engage in advocacy to secure this setting or other interventions? What kind of discussions did you have with your parents about your physical disability?
8. How would you best describe any modifications or devices that were helpful?
9. Did you receive academic and other support from your classmates?
10. What is your highest degree?
11. Which was the most difficult: the early grades, high school, college, or graduate school and why? In all your years of education what was the most significant obstacle?

Lifestyle

12. Are there specific activities which you avoid due to your disability?
13. Outside of work, which situations are most difficult for you due to your disability?
14. What forms of recreation or entertainment do you most enjoy?
15. What additional psychosocial stressor (such as traveling alone, mobility, meeting family obligations, etc.) do you believe is present in your life due to your disability?
16. How would you best describe any modifications or devices that were helpful?
17. Do you or have you utilize(d) the services of a personal attendant?
18. What are your major concerns or fears for the future with ageing?
19. If you had to rate your own self-concept (low, medium, or high), how would you rate yourself?

Employment

20. What is your current job title?
21. Describe your typical duties.
22. What do you consider the most important contributing factors to your professional success?
23. How would you describe your current remuneration: lower middle, middle, upper middle, upper?
24. Have you utilized ADA in securing or maintaining your current professional position?
25. Do you routinely use a computer at work?
26. Do you require modifications or adaptations to utilize this computer?
27. Is there a specific job task or duty that is difficult or requires some assistance?
28. Is transportation to/from work an issue?
29. Is your workplace generally accessible?
30. Do you feel that you would have progressed further in your chosen career if not for the presence of your disability?

Marriage and Family

31. How long have you been married?
32. At some point prior to your marriage did you fully explain the implications of your disability?
33. What, if any, issues concerning your disability were expressed by your in-laws?
34. In what, if any, life activities do you depend on your spouse?
35. Did your disability affect decisions on your family size?
36. Have you talked with your child(ren) about your disability? If so, at what age and in what detail did these discussions take place?

Medical

37. Did you receive occupational, speech, and physical therapy during the developmental years and did you consider it effective?
38. What specific health problems do you attribute to your disability?
39. Do you foresee additional health problems related to your disability as you age?
40. Are you currently taking any medications for the movement disturbance?

41. In choosing a family physician were there any special qualifications? Do you utilize a specialist (such as a neurologist)?
42. Are you utilizing any alternative medical treatments (chiropractors, massage therapists, etc)?
43. Do you believe any health problems are associated with your disability?
44. Has accessing insurance (life, auto, health) been more difficult because of your disability?

Future Considerations

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45. Have you factored your disability into your retirement and long-term financial plans?
46. Have you considered the type of living arrangement that would be most accommodative and beneficial after retirement?
47. Have you discussed with your physician or others the relationship between your disability and life expectancy?

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INFORMATION FOR AUTHORS

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